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Caring as Catalyst;

A Model for Health Possibilities

Brenda A. Becker

Submitted in partial fulfillment of the
Requirement for the degree of
Master of Arts in Nursing

AUGSBURG COLLEGE
MINNEAPOLIS, MINNESOTA

2004

Augsburg College
Department of Nursing
Master of Arts in Nursing Program
Thesis or Graduate Project Approval Form

This is to certify that Brenda A. Becker has successfully defended her Graduate Field Project entitled "Caring as Catalyst: A Model for Health Possibilities" and fulfilled the requirements for the Master of Arts in Nursing degree.

Date of Oral defense June 29, 2004.

Committee members signatures:

Advisor: Susan K Nash Date 6/29/04

Reader 1: Ruth C. Ernstedt Date 6/29/04

Reader 2: [signature] Date 6/29/04

Abstract

Caring as Catalyst;

A Model for Health Possibilities

Brenda A. Becker

June 29th, 2004

____ Integrative Thesis

_X__ Field Project

This graduate field project presents a conceptual model based on the theoretical frameworks of Brentano, Frankl, Rogers, Merry, Benner, and Wrubel and is designed to facilitate the life journey to more complex levels. The model has a foundation in chaos theory and in the search for meaning. Key concepts of catalyst, presence, polarization, and participation are defined and described. Presence is defined at three levels: physical, psychological, and therapeutic. Participation is defined as a sharing of the life and experience between nurse and person. Polarization, or change in pattern, is also defined at three levels: active, collaborative, and passive. The model was applied and examined in the context of the nurse interacting with women living with fibromyalgia through interviews and a health diary. The model was also evaluated by examining the women's life stories and perceptions after the project completion.

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For Bill. Even though you are halfway across the country, you are always here when I need a nudge in the right direction.

And, especially, for my parents, Linda and Lester Becker. I know I haven't always taken the easiest path, but you have always supported me no matter what I wanted to do.

"It is good to have an end to journey toward,

but it is the journey that matters in the end."

Ursula K. LeGuin

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Chapter I: Introduction

History and Background Contributing to the Project

From our very first day as nursing students, we concentrate on biology, pharmacology, and disease. We learn how to perform medical procedures and what the ideal outcome of those procedures should be. Students concentrate on rote knowledge through cause and effect relationships. The goal is to find the right answer to the immediate question at hand.

But then we take a class called nursing theory. There are no concrete 'right' answers, but an opportunity to examine the contributions to the profession of nursing and to reflect on our own practice. Just as we dissect anatomical specimens to comprehend how the body functions, so we attempt to examine existing theory to understand how nursing can affect the people we interact with. This is a complete shift in thinking, especially at the undergraduate level. The study of theory is challenging and beneficial, as we ideally find a theory that partially or fully complements and supports our unique viewpoint on nursing.

I used to view theory as unpleasant to study and apply, but necessary for the nursing profession to continue to develop. Theory was a class which was required as part of the curriculum, but was not viewed as being as important as the science courses. I struggled with understanding the benefit or the purpose of studying theory. It seemed unrealistic, too idealistic, and failed to capture what it was I was experiencing with my patients, and within my own life.

In my graduate studies, I eventually came to use the work of Martha Rogers as the foundation for my nursing practice. Rogers' Science of Unitary Human Beings (Rogers,

1970) was the theory that seemed to capture the complexity and ever changing nature of life through open, interactive energy fields. But even then, Rogers' work did not seem to capture it completely. There was something else missing that would complete the picture.

Purpose and Significance of the Project

This project served as a formal means to capture and define some of my own life experiences as a patient, a nurse, and an educator in a formal conceptual model. "A conceptual model is...developed when generalizations about specific observations are formalized..." (Fawcett, 1995, p. 3). Personal life and professional practice offers a forum for each of us to develop our own way of relating to nursing and to the people whom we interact with. These experiences were explained and evaluated in a more formal structure so others may benefit from what I have experienced.

The significance of the project is that it will provide a fresh perspective on the art of nursing, which is the unique complement of the science, as we interact with people in a variety of settings. The art of nursing is just as critical as the science of nursing and is necessary for the future of the profession. The strength and uniqueness of our profession lies within nurses, not merely in the assigned tasks, in whatever context they may practice.

The purpose of the paper is to develop, present, and evaluate a new and unique conceptual model which will guide future nursing practice and research. "A conceptual model of man provides a way of perceiving the life process and establishes a foundation for continuing development of relevant research and significant utilization of investigatory findings" (Rogers, 1970, p. vii). It will provide future nurse researchers

with a framework to explore individual experiences and to understand the impact those experiences and resulting meanings have on the whole individual.

This paper will also begin to bridge nursing to the sciences of chaos, self-organization, and complexity (Briggs & Peat, 1989; Gleick, 1987; Merry, 1995). These sciences focus on whole systems, feedback, and unpredictable change. It will provide a complementary view to the linear and reductionary theories of medical science to capture the complexity and wholeness of human life. Nursing can use the tenets of these sciences to advance the development of the profession beyond our current theoretical foundations.

The project resulted in a new conceptual model. "Conceptual models of nursing, then, are the formal presentations of some nurse's private images of nursing. The proponents of nursing models maintain that use of a conceptual model facilitates communication among nurses and provides a systematic approach to nursing research, education, administration, and practice" (Fawcett, 1995, p. 5). This conceptual model defines, interprets, and provides visual structure to human experiences and meanings in everyday life.

The conceptual model provides a unique interpretation of the relationship of the metaparadigm concepts of nursing: person, environment, health, and nursing (Fawcett, 1995). Each concept has unique and specific characteristics within the context of the model. The definition and application of the current metaparadigms of nursing are enriched by the application of this conceptual model. The relationships of the metaparadigm concepts within this model are presented in text and visual form.

Martha Rogers' Science of Unitary Human Beings (1970) is the primary nursing theory used as the foundation of the conceptual model. Some of her concepts, such as

energy, pattern and irreducibility, have been complemented and supported by theorists from other disciplines preceding and succeeding her, such as these from physics, psychology, and philosophy (Bohm, 1994; Brentano, 1929; Benner & Wrubel, 1989; Frankl, 1984). "Conceptual models evolve from the empirical observations and intuitive insights of scholars and/or from deductions that creatively combine ideas from several fields of inquiry" (Fawcett, 1995, p. 3). This conceptual model is Rogerian in foundation and framework (Rogers, 1970, 1992), but it is a unique blend of current and historical disciplines.

Application and evaluation of the project.

The conceptual model was implemented and evaluated with women living with fibromyalgia. Several health disparities exist with this group. Fibromyalgia is a subjective, invisible disease. There is no single lab test to diagnose it (Paget, Gibosky, & Beary, 2000). Subjective criteria exist to conclude the diagnosis of fibromyalgia (Jacobsen, Danneskiold, & Lund, 1993; Fransen & Russell, 1996; Hill & Ryan, 2000; Rome, 2002; Viitanen, Ronni, Ala-Peijari, Uoti-Reilama, & Kautiainen, 2000), but barriers often exist between person and diagnosis, such as physician disbelief, lack of education, and variations in presentation of symptoms due to life stressors (Hellstrom, Bullington, Karlson, Lindqvist, & Mattsson, 1998). Even people who have the diagnosis still struggle with life and role expectations and, again, face possible disbelief from family, friends, and employers (Hallberg & Carlsson, 2000). It is a disease which offers many challenges, and can result in positive or negative life experiences.

This conceptual model was applied and evaluated via interviews describing the lived experiences of fibromyalgia patients and the interactions the participants have had

with the health care system. "Through meditations...and other interpretive acts we assign meaning to the phenomena of lived life" (van Manen, 1990, p. 37). Interviews were also utilized to evaluate the overall project experience.

A structured health diary activity provided current information on the participants' daily experiences. Diaries are designed to have participants "write down specific behaviors on a daily or more frequent basis, describe the circumstances, and react in writing to the activity" and their purpose is "to track changes in specific behaviors over time" (Dellasega, 2001, p. 20). They provide insight into the physical, spiritual, mental, and emotional states of an individual (Day, 2001; Judith & Vega, 1993, Vander Zyl, 1997) and their perceived health status (Wykle & Morris, 1988).

The health diary of Dr. Karen Moore Shaefer (1997) was the formal tool utilized in this project. The health diary used a combination of visual analogue scales, qualitative descriptors, and open-ended questions to assess demographics, sleep patterns, fatigue, pain, stress, weather, activity, and effectiveness of interventions,

Diaries provide significant psychological benefit. They promote "coping with repressed emotions, promoting insight into personal coping styles, learning new ways to express feelings...improving self esteem, and conducting a life review" (Dellasega, 2001, pp. 20-21). Diaries can also promote self direction and control through personal insight and awareness (Schaefer, 1997). The recording of events, thoughts and feelings in a written format provides a structure for reflection and analysis of the experiences (Vander Zyl, 1997).

As technology is making the world a more complex, connected place, the people living in that place are changing as well. In order to continue to assist people in a

complex world, nursing must change, build on the existing research, and continue to develop theories and conceptual models to support the changes in human lives and technology. This conceptual model opens the door to complexity science as a tool for nursing and the potential to understand where we are going based on where we have been.

Chapter II: Review of Relevant Literature

Fibromyalgia: Definition, Impact, and Treatment

Fibromyalgia is a disease process embedded with suffering. It is subjective, often nebulous, and can be difficult to define. "How little the real sufferings of illness are known or understood" (Nightingale, 1969, p. 102). The word "fibromyalgia" comes from the Greek words *algia*, or pain, *myo*, or muscle, and the Latin word *fibro*, which refers to the connective tissue of the body (Fransen & Russell, 1996; Starlanyl & Copland, 2001). As the etiology is unknown and the diagnosis challenging, people may struggle with coping and adapting.

The estimate of incidence runs as high as two to four percent of the population of industrialized nations (Paget, et al., 2000). It is estimated nearly eighty percent of those people are women. The diagnosis is evenly distributed among all age groups but the most frequent age of onset occurs between the ages of 20 and 40 (Hellstrom, Bullington, Karlsson; Lindqvist, & Mattesson, 1999). It affects all cultures and socioeconomic groups (Fransen & Russell, 1996).

The American College of Rheumatology (ACR) has classification criteria for the diagnosis of fibromyalgia (Wolfe, Smythe, Yunus, Bennett, Bombardier, Goldenberg, et al., 1990). Those criteria include: the presence of widespread pain for more than three months and pain that can be caused by pressure of approximately 4 kg (Jacobsen, et al., 1993; Paget, et al., 2000) at eleven or more specific pressure sites, called tender points (Fransen & Russell, 1996; Soderberg & Lundman, 2001). Tender point presentation has a direct correlation state of distress at the moment of assessment (Paget, et al., 2000).

Many physicians challenge the stringency of the tender point criteria. Winfield (1999) argues the criteria for diagnosis is problematic because they can be manipulated, have no exclusions, and are based on self-report. Physicians argue the criteria are too inflexible and the diagnosis can exist without meeting the tender point criteria (http://www.mayoclinic.com, 2004). Tender point presentation is a definable criteria for research but may not be the absolute identifier in clinical practice (Fransen & Russell, 1996).

The Consensus Document on Fibromyalgia: The Copenhagen Declaration (Jacobsen, et al., 1993) further elaborated on the ACR guidelines. "Fibromyalgia is a painful, non-articular condition, predominantly involving muscles; it is the commonest cause of chronic, widespread musculoskeletal pain. It is typically associated with persistent fatigue, non-refreshing sleep, and generalized stiffness" (Jacobsen, et al.,1993, p. 297). This document also reinforced the strict classification of criteria for research protocols, when, in actuality, many patients with the symptom cluster have less than 11 tender points (Jacobsen, et al., 1993). Fibromyalgia is a "diagnosis of exclusion" (Paget, et al., 2000, p. 366) due to the fact there is no single laboratory test that can accurately provide a diagnosis.

There are numerous other signs and symptoms of fibromyalgia. None of them is directly life threatening, but the unmanaged, cumulative effects can make it challenging for a person to lead a productive life. Other signs and symptoms include fatigue and sleep disturbances, irritable bowel syndrome, increased sensory sensitivity, headaches and migraines, irritable bladder, numbness or tingling sensations in the extremities, mood fluctuations, sleep apnea, and restless legs syndrome (Fransen & Russell, 1996; Hill &

Ryan, 2000; Rome, 2002; Viitanen, et al., 2000). The overall symptom cluster is referred to as fibromyalgia syndrome (FMS) (Fransen & Russell, 1996; Starlanyl & Copeland, 2001; Viitanen, et al., 2000).

Two schools of thought exist concerning the symptomology and the causes of fibromyalgia. One is the psychological/biomedical approach, which attributes the symptomology to the body's response to stress (Fransen & Russell, 1996). Other potential biomedical causes of fibromyalgia include sleep disturbances, spinal cord injury, infection, and abnormalities in the sympathetic nervous system (http://www.mayoclinic.com, 2004).

Giovengo, Russell, and Larson (1999) also discussed this potential biomedical cause of the pain of fibromyalgia. These researchers found increased levels of nerve growth factor in people with fibromyalgia at inflammatory sites and it may be a cause of hyperalgesia, or "pain sensations (that) are intensified and amplified" (Starlanyl & Copeland, 2001, p. 6). Abnormalities of neurotransmitters in the cerebrosprinal fluid of people with fibromyalgia may account for the differences in pain processing and perceptions (Fransen & Russell, 1996; Paget, et al., 2000).

Another approach to the cause of fibromyalgia is that it is essentially a somatoform disorder, or "a group of disorders in which physical symptoms suggesting physical disorders for which there are no demonstrable organic findings or known physiologic mechanisms, and for which there is positive evidence, or a strong presumption that the symptoms are linked to psychological factors" (http://cancerweb.ncl.ac.uk/omd/, 2004). This definition reflects fibromyalgia as an exclusive condition of the mind when no findings exist for a physiological cause.

McBeth, McFarlane, Benjamin, Morris, and Stilman (1999) have proposed that the cause of tender points, which is a defining characteristic of fibromyalgia, is a link between past life events and subsequent manifestations of symptoms of unknown, or biologically unexplainable, origin. The researchers found individuals with greater than five tender points had experienced greater somatic symptoms, experienced higher levels of fatigue, utilized medical care more often, had more childhood abuse and experiences than individuals with fewer than five tender points (McBeth, et al., 1999). Rome (2002) also states fibromyalgia may be caused by "physical or emotional trauma" (p. 19). These researchers are expanding on the mind/body connection in the presentation of fibromyalgia.

Fibromyalgia affects every aspect of an individual's life. As the symptomology is powerful and invisible to others, Soderberg and Lundman (2001) defined it as "the choreographer of activity and relationships" (p. 626). It affects working life, social life, family life, and the daily life pattern (Soderburg & Lundman, 2001). These effects can impact self-esteem and sense of self, which are magnified by disbelief from family and health care providers (Starlanyl & Copeland, 2001). As fibromyalgia has so many different symptoms and can affect individuals differently, it can be very stressful (Rome, 2002).

Okifuji, Turk, and Sherman (2000) found the people with fibromyalgia in their study had a higher incidence of depression than healthy people. However, the researchers also found fibromyalgia and depression did not automatically exist together. People who lived with someone and/or had a history of physical therapy were less likely to be depressed. Several other researchers have reinforced the incidence of depression in

patients with fibromyalgia (Burckhardt, O'Reilly, Weins, Clark, Campbell, & Bennett, 1994; Cudney, Butler, Weinert, & Sullivan, 2002; Hassett, Cone, Patella, & Segal, 2000). These researchers also stated untreated depression could adversely affect an individual's ability to cope with the symptoms.

Bernard, Prince, and Edsall (2000) describe a "spiraling effect" (p. 48) of depression and relationship to life and other activities. A person may decrease his/her activities due to fibromyalgia symptoms, which in turn worsens the depression and isolation. As the pain experience guides life, women may become "preoccupied with their pain" (Hallberg & Carlsson, 2000, p. 34). The deeper depression even more markedly affects life activities and so on. It is challenging to truly decide if depression causes fibromyalgia or the results and symptoms of fibromyalgia cause depression (Hill & Ryan, 2000).

Bernard, et al., (2000) also found wide spread effects of fibromyalgia pain on women's lives. The main areas of impact these researchers discovered were mental health, relationships, career, personal relationships, and social support. The current quality of life was rated significantly lower than the reported score prior to diagnosis.

Depression, exacerbation of physical symptoms, and quality of life can be directly affected by the body's ability to restore itself. All human beings need adequate sleep to heal and continue functioning. Fibromyalgia prevents normal sleep and restorative healing time.

People with fibromyalgia do not cycle through normal sleep patterns. Fransen & Russell (1996) stated sleep disturbances exist in ninety percent of people with

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fibromyalgia. They may experience different types of insomnia, such as problems falling asleep, waking early in the morning, restless sleep, and inability to fall back to sleep.

These conditions are a result of an interruption of deep, or stage 4, sleep with active brain activity (Starlanyl & Copeland, 2001). They experience bursts of alpha waves in deep sleep cycles, which confuses the body and mind by triggering waking behaviors and bypassing the healing cycles (Fransen & Russell, 1996). Alpha waves occur during waking periods and delta waves occur during deep sleep cycles (Starlanyl & Copeland, 2001). This alpha-delta EEG anomaly has been discovered in most patients with fibromyalgia (Jacobsen, et al., 1993; Fransen & Russell, 1996; Hill & Ryan, 2000).

As this sleep stage is interrupted, the normal restorative processes at the cellular level do not occur to their fullest potential (Starlanyl & Copeland, 2001) which in turn results in decreased attention, reaction time, concentration, and abnormal waking after unrefreshed sleep (Jacobsen, et al., 1993; Fransen & Russell, 1996). People who do not progress through the usual patterns of sleep do not have deep periods of body and mind healing.

Pain, depression, and lack of sleep affect the biological state of a person. These symptoms can also affect social interactions and may impact their formal and informal roles, contributions, and relationships with peers and family. Fibromyalgia affects the individual from within, and affects support networks as well.

Fibromyalgia is an unseen disease process, invisible to the support network of the person affected and difficult to isolate by health care practitioners. People may doubt what they cannot see for themselves. "Similarly for the medical profession, it is a perceived disturbance of normal function that mobilizes the physician" (Barnlund, 1976,

p. 718). Hallberg and Carlsson (2000) discovered women's irritation with people who "explicitly or implicitly doubted their pain" (p. 34). This irritation is often internalized and not shared with existing support systems or health care practitioners.

The lack of validation by others has a deeper effect than mere irritation. Soderberg, Lundman, and Norberg (1999) stated that personal integrity was compromised when credibility was questioned by those around someone living with fibromyalgia. This violation of integrity invalidates a personal dignity, which is a unique characteristic of all human beings (Soderberg, et al., 1999). Women living with fibromyalgia under these circumstances are putting energy into maintaining their dignity which could better be utilized living their lives.

Hellstrom, et al., (1998) found five themes within the interactions of patients living with fibromyalgia and their physicians: managing clinical uncertainty, adhering to the biomedical paradigm, prioritizing diagnostics, establishing an instrumental relationship, and avoiding recognizing fibromyalgia as a biomedical anomaly. As fibromyalgia is difficult to diagnose, physicians often felt frustrated and powerless. The physician institutes a diagnosis to prevent being viewed as incompetent, to exclude other options, and to provide a label to quantify the course of treatment. The physician remained grounded in a biomedical model and seemed not to entertain the possibility fibromyalgia may be "expressions of a life situation difficult to manage" (Hellstrom, et al., 1998, p. 235). Overall, the physicians attempted to isolate and reduce fibromyalgia to a concept independent from the person.

Women are often the focus of reductionism. Their accounts are frequently dismissed by health care providers based entirely on their assumptions based on gender,

as in Howell's (1994) experience with men and women with migraines. Women who came to the emergency department complaining of severe episodes of chronic migraine or tension-vascular headaches were treated in a very derogatory manner by the physicians and nurses (Howell, 1994). "Men are more likely to receive surgery in response to pain complaints, whereas women are more likely to receive medications to treat anxiety or depression" (Fishman & Berger, 2000, p. 22). Arslanian-Engoren (2000) also found women were less likely to receive aggressive treatment and a diagnosis of myocardial infarction due to health care providers' perceptions and assumptions. This health disparity shows a gender bias based on a practitioner's interpretation of the patient's experiences.

Women living with fibromyalgia desire specific things from their health care providers. They want support through empathy and listening and for the health care provider to believe the disease really exists (Bernard, et al., 2000; Hellstrom, et al., 1998; Hellstrom, et al., 1999). In addition, education of health care providers on diagnosis, treatment, and supportive therapies was important (Bernard, et al., 2000). Education of health care providers may give them the tools to treat the person instead of only a diagnosis.

The reduction of fibromyalgia to a set of signs and symptoms, and a resulting cure, loses the experience, meaning, and essence of what it is to live with a chronic condition. As experience is interconnected (Brennan, 1987), it affects the person as a whole. Therefore, the experience is part of the life, coping, and transition to health. "To give patients the feeling that they are a problem, a disease, or an intriguing curiosity rather than a human being is to undermine the process of sharing meanings" (Barnlund,

1976, p. 719). The overall experience cannot be isolated and placed aside, reduced to inconsequential, meaningless events.

As we search for meaning in our experiences within our lives, the meanings and experiences become part of us, which in turn affects our future choices. "The meaning in turn reflects the past experiences and future expectations of the patient" (Barnlund, 1976, p. 718). The pursuit of meaning may serve a purpose as well.

The search for meaning may provide relief from the disease (Benner & Wrubel, 1989) and promote hope (Ersek & Ferrell, 1994). "They are trying to give their illness a meaning and coherence. To seek explanation and understanding gives the participants relief" (Soderberg, et al., 1999, p. 584). It may be hypothesized if adaptive, or positive, meanings provide relief; maladaptive, or negative, meanings may aggravate or intensify the pain.

Howell (1994) found women living with fibromyalgia and other chronic pain diagnoses progressed through four stages: "the pain takes over, filling my life with pain and despair, filling my life with new hope, and fulfilling my life with pain" (pp. 106-107). Each stage was found to have distinct, defining characteristics. Some women progressed through all four stages by utilizing positive coping strategies. Howell found many women did not progress to the healthy levels and instead remained in illness through negative strategies such as blame, doubt, minimizing, and isolation from others and self. The isolation in turn led to despairing. "The women described feelings of 'becoming' chronic pain and being trapped" (Howell, 1994, p. 109). Barnlund (1976) suggests these experiences will influence their future perceptions and expectations.

Soderberg and Lundman (2001) found women with fibromyalgia consciously tried to transcend the limitations of the disease even though they knew it would aggravate their symptoms. These women completed activities in order to be seen as normal by others which enhanced their self esteem. Hallberg and Carlsson (2000) also found women sought out self initiated activity to help reduce pain. These two researchers show women can choose a positive way to live with fibromyalgia.

People may give a label, and subsequent meaning, to the suffering which may be adaptive (positive) or maladaptive (negative) (Bernard, et al., 2000). Positive coping strategies are utilized to live and adapt with a nebulous disease process. Exercise, talking to a friend or family member, and prayer were found to be the top three positive coping strategies (Bernard, et al., 2000). Other strategies included hobbies, talking to a professional, and relaxation techniques. Hobbies and exercise were the major coping strategies impacting quality of life. Brown and Nicassio (1987) found that more active coping strategies resulted in a higher level of control of their health and decreased levels of depression, pain, helplessness, and functional impairment. These researchers have shown that positive adaptive coping strategies can directly influence quality of life.

However, the labels and subsequent meanings can also be maladaptive or negative (Hassett, et al., 2000). Women with fibromyalgia scored higher in depression, catastrophizing behaviors, and reports of pain than rheumatoid arthritis patients on various assessment tools. "Catastrophizing is a correlate of psychological vulnerability in which people feel helpless about their ability to impact internal and external events successfully" (Hassett, et al., 2000, p. 2494).

Burckhardt, Clark, and Bennett (2001) also found younger women had higher levels of catastrophizing behaviors than older women. Women living with fibromyalgia may catastrophize their experience to make a seemingly invisible entity tangible. "Meanings do not come from the world but are assigned to it by every interpreter, and it is he who is the final arbiter of events" (Barnlund, 1976, p. 717).

Amir, Neumann, Bor, Shir, Rubinow, and Buskila (2000) found women with fibromyalgia utilized an avoidant coping strategy as compared to a healthy control group, women with rheumatoid arthritis, and women with low back pain. The women in the non-control groups also stated more anger, had self directed anger, and were at higher risk for suicide than the healthy group. Brown and Nicassio (1987) also found "passive coping was consistently related to poorer adjustment" (p. 61). The type of coping used directly resulted in changes in life behaviors.

Several other coping themes were revealed in other studies. "To put a label on suffering gives it meaning" (Hellstrom, et al., 1999, p. 15). Celiker and Borman (2001) discovered that rheumatoid arthritis and fibromyalgia patients share helplessness. Hallberg and Carlsson (2000) found women with fibromyalgia used resignation, passivity, and escape behaviors as pain coping strategies. Resignation "reflects feelings of hopelessness and lack of control over the pain" (Hallberg & Carlsson, 2000, p. 33). Alcohol and nonprescription drugs are also used as an escape strategy for women living with fibromyalgia (Bernard, et al., 2000). Hellstrom, et al. (1999) even hypothesized that the pain and symptoms were part of a "deliverance strategy" (p. 14) used to avoid events or things which seem unmanageable. "As long as one has not tried to do

something one finds desirable, the hope of being able to do so is still intact" (p. 15). The coping methods defined in these studies are as diverse as the people experiencing them.

The meanings people ascribe to their experiences influence what coping methods are available to them (Benner & Wrubel, 1989). Some meanings may conflict with others or be stressful, which in turn impacts the coping potential available. If current coping strategies are not achieving the desired benefit, people can look for the conflicts among or absence of personal meanings.

As the etiology of fibromyalgia is unknown, there is no absolute course of treatment, and no cure (Bernard, et al., 2000; Viitanen, et al., 2000). The current management of fibromyalgia is directed toward the minimization of symptoms in order for a person to live his/her life to the highest potential (Cudney, et al., 2002; Hill & Ryan, 2000). There are two components to the current treatment program for symptom management: pharmacological interventions and self care (http://www.mayoclinic.com, 2004). Support groups are one way to learn what programs have been successful with other people. Complementary therapies may also be beneficial in a management program.

Pharmacological interventions are symptom and individual specific. As fibromyalgia has a cluster of symptoms, health care providers must be attuned to the overall pharmacological picture to provide the most benefit with the least interactions and side effects. They must also be evaluating regimes the person may be utilizing on his/her own, such as over the counter, herbal, or dietary regimes, as there are potential interactions among all of these modalities (Younkin, Sawin, Kinninger, & Israel, 1999).

However, medication management of these symptoms is not the only answer. Other treatment modalities such as exercise, diet, and following an individualized plan of self directed management can help reduce the frequency of intense, aggravation of symptoms, or flares (Starlanyl & Copeland, 2001). The individualized plan targets symptom management through the recognition and reduction of potential triggers. The holistic care of the person assists in reducing stress levels, which in turn have an effect on the overall person and disease process.

A structured, proactive plan may make living with fibromyalgia much easier. Starlanyl and Copeland (2001) recommend developing a Wellness Recovery Action Plan (WRAP) to utilize when symptoms are first noticed. An individual WRAP provides a person with fibromyalgia a set of tools, goals, and strategies, both proven and potential, to maximize wellness. A WRAP includes:

1. "Monitoring, uncomfortable, or distressing symptoms, unhealthy habits, or behavior patterns;
2. Reducing, modifying, or eliminating those symptoms or habits through planned responses;
3. Creating the life change you want;
4. Planning advanced directive that instructs others on how to make decisions for you, take care of you in case your symptoms escalate to the point where it is impossible for you to take care of yourself". (Starlanyl & Copeland, 2001, p. 183).

The authors reported individuals who use this system state their wellness and overall quality of life increases when they use the WRAP.

Support groups which specialize in the challenges of fibromyalgia could be a resource for building a WRAP plan. Groups can provide insight into approaches others may not have tried as well as understanding through mutual experience. "One can feel less stigmatized by illness when one knows that others share the same fate...people often feel that only others who have experienced the same illness can understand and that understanding is therapeutic" (Benner & Wrubel, 1989, pp. 139-140). They may also be beneficial in sharing information, referrals to practitioners, and the validation of the experience (Fransen & Russell, 1996; Rome, 2002; Starlanyl & Copeland, 2001). Peer counseling or involvement of family and significant others could also help in building and maintaining a WRAP.

Some complementary therapies which have been shown to reduce stress and pain include Reiki, movement therapy, physical therapy, reflexology (Starlanyl & Copeland, 2001), chiropractic manipulation, massage therapy, acupuncture and acupressure, and osteopathy (http://www.mayoclinic.com, 2004). Journaling, prayer, music, and imagery may also reduce stress and the resulting cascade of symptoms (Fransen & Russell, 1996; Starlanyl & Copeland, 2001; Wallace & Wallace, 2003).

An integrated, multidisciplinary approach can address the complexity and impact of fibromyalgia on all facets of daily life and self (Byas-Smith, 1997). Each expert on the health care team can provide input on a unique plan specific for that individual. Only after a health care provider understands the person, his/her presentation, and the resulting collaborative plan, can a person find his/her own path to health.

Most Western medicine is grounded in concrete science. Practitioners often are looking for the link between "mathematical and experimental proof" (Brennan, 1987, p.

21). It is a causal, linear, reductionary line of thought which separates the disease from the individual to eradicate and cure it. "Modern medicine... is hell bent on cure and has no interest in the body's inherent art. It wants to eradicate all anomalies before there is a chance to read them for their meaning" (Moore, 1992, p. 155). These meanings drive how people cope with trauma and illness.

Defining and Utilizing Coping Strategies

Coping is a unique experience. Many professions have attempted to define and structure what "appropriate" or ideal coping is. Benner and Wrubel (1989) define coping as "what people do when personal meanings are disrupted and smooth functioning breaks down. Coping is always bounded by the meanings and issues inherent as what counts as stressful." (p. 408). However, it is difficult to capture because individual variations of coping are as ingrained in our lives as the search for meaning.

Stress is a trigger for coping. Benner and Wrubel (1989) define stress as "the disruption of meanings, understanding, and smooth functioning so that harm, loss or challenge are experienced, and sorrow, interpretation, or new skill acquisition is required" (p. 412). Not all events are universal stressors to each person. People prioritize their lives and contributions in different manners. Therefore, what is stressful to one will not be stressful for another.

Things which matter to people and have meaning are important in their daily lives. Stress occurs when those things that they care about become disjointed. "Stress is the experience of the disruption of meanings, understanding and smooth functioning. Coping is what one does about the disruption" (Benner & Wrubel, 1989, p. 62). People may experience stress over family, finances, or their job, because those things hold

meaning to them and are important. "Stress is the inevitable result of living in the world where things matter to one" (Benner & Wrubel, 1989, p. 61). People feel varied levels of stress related to the degree of importance.

After the stressful event, or stressor, we try to protect or reattain those things that we care about. We reorganize our behaviors, environment, and emotions to reduce the stress and preserve our priorities. "Stressful life events require a significant lifestyle adaptation or coping behavior" (Smith & Maurer, 2000). Stressors can be life changing. We may reorganize to a new set of priorities after realizing our perception of the important things in life has changed significantly.

Coping styles which have a caring component may serve a transformative purpose. People are able to bring interpretations from the past to the present, or futurity (Benner & Wrubel, 1989), and see if they still ring true, or need modification based on current life experiences. "This has a distinct transformative advantage over always avoiding the context of the emotion because reinterpretation in light of present circumstances and knowledge offers the possibility for growth or new understanding, or new coping options" (Benner & Wrubel, 1989, p. 97). Coping, which is grounded in the things people care about, reconnects us with the meanings of the events in our lives.

In contrast, coping styles which distance us from our emotions through isolation lose the benefits of those emotions. "The person who learns to 'manage' (ward off, distance) emotions effectively eliminates the guidance and direction provided by these emotions" (Benner & Wrubel, 1989, p. 60). People may attempt to protect themselves from more stress or trauma by distancing themselves from the associated emotion and can end up in a spiral of reoccurring events.

As people, we are continually searching for the meanings within our lives and coping assists us in attaining goals and protecting things that we care about through emotions, learning, and constant change. A meaningful life found through children, contributions to society, and personal growth can be impacted, and threatened by pain.

The unique experience of pain

Nearly every human being experiences pain at various points in his/her life. Pain may be related to many different things such as injury, health care intervention, or disease. The word "pain" has both Greek and Latin roots. *Poine*, of the Greek, and *poena*, of the Latin, both refer to "a penalty or punishment" (Livingston, 1998, p. 145). It can protect us, be a warning sign, or a result of an internal or external influence. "Pain is the built in mechanism that alerts us to correct a situation...Pain teaches us to ask for help and healing" (Brennan, 1987, p. 145). It is "a universal human experience" (Villarreul, 1995, p. 263).

Pain is a multidimensional concept. It is a combination of physical sensations partnered with emotions and previous experiences (Cleland & Gebhart, 1997). Culture, familial upbringing, societal expectations, and gender also have an impact on the pain experience (Fishman & Berger, 2000; Smith & Maurer, 2000; Villarreul, 1995). Pain can be a difficult phenomenon to capture, examine, and evaluate because of the complexity of these factors.

The assessment of the pain experience by the health care provider, family, or friends can be tainted by their own coping methods and pain experiences. The person who is assessing the patient's pain experience has expectations the patient will experience and express pain in the same way he/she does (Smith & Maurer, 2000). These

assumptions could result in disbelief, stereotyping, and undertreatment (Villarruel, 1995). If the patient and the health care provider are making assumptions about the nature of the pain and the expectations of treatment, pain control programs may not be successful.

Health care providers attempt to capture the pain experience through a variety of assessment tools such as the McGill Pain Questionnaire, numeric rating scale, picture scale, verbal rating scale, and visual analogue scale (Karoly & Jensen, 1987; Kingdon, Stanley, & Kizior, 1998; Turk, 1997). The pain scales provide some consistency in evaluating pain by providing a framework of relative evaluation to different health care practitioners. It also attempts to provide a quantitative measure to a highly qualitative experience. "People in pain must rely on their language skills to describe what they are feeling. Inevitably, their descriptions don't do justice to what they are going through, and so doctors....may be skeptical of the severity of their pain" (Fishman & Berger, 2000, p. 16). However, the qualitative measurement of pain is not a complete evaluation of the pain experience and it can be difficult to show variations in pain levels due to specific interventions.

The concept of pain is a merging of the biological sensations with the perceptions and memories of the mind. "Pain is a consummate mind/body event where sensation and emotion become inextricably intertwined; it is impossible to say where the realm of physical pain ends and psychic suffering begins" (Fishman & Berger, 2000, p. xii). The physical sensations are coupled with the perceptions of the mind to formulate a personalized experience.

The perception of pain is more than just the biological response to tissue injury. Pain is an experience which is subjective in the view of the person experiencing it. "I

could understand how important it was for a physician to be able to distinguish between a patient's pain and his psychological reaction to it because these two components of suffering required different modes of treatment" (Livingston, 1998, p. 4). "For the patient there is no distinction between perceived pain and real pain" (Barnlund, 1976, p. 718).

Pain also encompasses the interpretation and subsequent meaning of the experience. Two people with similar types of pain will not experience, interpret, and give associated meanings in the same way (Smith & Maurer, 2000). "Each person in pain experiences that pain in a particular way that has a special meaning. The meaning may not be fully conscious, but it is present" (Fishman & Berger, 2000, p. vii). The uniqueness of the pain experience is a challenge to the quantification of pain for health care providers.

Acute pain can serve a protective function. It is a warning to our bodies to be aware more potential injury is possible or as a reaction to tissue damage from external forces. "Acute" is derived from the Latin word for needle (Rome, 2002). There is an immediate biological response to tissue injury to prevent more damage.

Acute pain usually resolves when the original tissue injury has completely healed. However, the pain may continue well past the final stages of tissue healing. Pain which lasts longer than six months is considered chronic pain (Rome, 2002; Turk, 1997). "Chronic" is derived from the Latin word for time (Rome, 2002). Pain may remain for much longer than what is expected after the healing process is complete (Fishman & Berger, 2000).

Chronic pain can be intangible, and therefore unable to be verified, by others. In all outward appearances, the person should be fine. The original injury has healed or there is no ascertainable cause for the pain. Health care providers may have exhausted all diagnostic efforts with no viable results. The person knows he/she hurts and something is wrong, but their doctors may not know why. Without a concrete cause, treatment can be a trial and error effort.

The chronic pain experience also has an impact on how people view themselves. "The common denominator of their suffering frequently entails a sense of loss: loss of function, loss of daily routine, loss of good health, loss of a feeling of control, loss of autonomy, or the loss of feeling invulnerable" (Fishman & Berger, 2000, p. 15). Chronic pain can affect their quality of life (Turk, 1997).

Rome (2002) describes the behavioral and emotional cycles of chronic pain. The behavioral cycle shows how chronic pain impacts personal routines. (Appendix A). The emotional cycle is just as much of a rollercoaster as the behavioral cycle. Our emotions tie in to how we feel physically, and may peak and valley based on how we feel. (Appendix B). We are constantly changing our activity level and emotional states through that connected relationship.

Fishman and Berger (2000) also describe the emotional effects of suffering due to chronic pain. Just as the body can develop a tolerance to medication, a person may become conditioned to chronic pain and the subsequent effects. The cycle of treatments and resulting failures becomes something people become accustomed to. If treatments do not work, people may stop activities which trigger or magnify the pain. The subsequent behavior may affect their relationships, job, and daily functions.

Health care professionals cannot treat pain without treating the person in his/her entirety. "Human beings are more than and different from the sum of their parts" (Rogers, 1970, p. 46). This is especially true for people with chronic pain. Ferrell (1995) has developed a conceptual model that illustrates the impact of pain on quality of life. Pain impacts physical, psychological, social, and spiritual well being. These four concepts are cornerstones of life and if they are impacted, the whole individual is affected. The pain, emotions, and feelings have become so interrelated that the person cannot be effectively treated by focusing on one component.

NEED FOR THE CONCEPTUAL MODEL

Nursing has proven itself as a contributing profession in the scientific world. It has increased the amount and application of research based practice. However, the art of nursing is just as important as the science of nursing. "New dimensions of artistry are achieved as the science of nursing grows and is incorporated into practice" (Rogers, 1970, p. 121). This conceptual model renews the art of nursing and its role in the care of people through scientific tasks and research based practice.

This conceptual model could be utilized with any person at any point in an interaction with a nurse or other health care provider. It is especially applicable for people living with fibromyalgia due to the stigma, nebulous symptomology, and challenges that exist for diagnosis and daily life. "Human illness is not only a physical condition but a symbolic one as well...every medical problem is in part a symbolic one" (Barnlund, 1976, p. 717). The conceptual model is the unique approach to health which nursing could provide. It complements and supports medical, pharmacological, and physical interventions.

Chapter III: Development of the Conceptual Model

Theoretical Underpinnings of the Conceptual Model

Several significant theorists in their respective fields provide the underpinnings for this conceptual model. Martha Rogers, Uri Merry, Viktor Frankl, Franz Brentano, Patricia Benner, and Judith Wrubel are each experts in their respective fields who are linked by one common concept: irreducibility. "Nursing's central concern is with man in his entirety" (Rogers, 1970, p. 41). This phenomenon is the common bridge among the different fields of nursing, complexity science, philosophy, and psychology and provides one of the major premises of this conceptual model.

Chaos, self organization, and complexity science also support the irreducibility of individuals. The concept of irreducibility is not synonymous with strict, unchanging, order, but is a way to capture the uniqueness of each individual through wholeness and growing complexity. As people are irreducible, we are both greater than the sum of our parts and much more than one isolated part.

Chaos is not a concept people tend to embrace. The word has a connotation of disorder, crisis, or turmoil. The actual denotation of "chaos" is "unpredictable change" (Merry, 1995, p. 11). It is interwoven with the framework of order and certainty and captures humanity. Chaos is not negative; it is just one characteristic of diverse and complex systems.

Chaos is a beneficial phenomenon to human beings. Strict order deters change and movement to higher states of complexity. "Without the randomness of chaos, the rich variety and diversity of evolution would be stifled and throttled. Chaos is the rich

soil from which creativity is born" (Merry, 1995, p. 13). Chaos provides the clearing for systems to restructure to higher levels.

Chaos and unpredictable change can be frightening. People like a sense of order, certainty, and expectation within their daily lives. When things are ordered, they are predictable. Predictability gives some measure of control and security, which is a basic need (Merry, 1995). We create structure and frameworks in our homes, our jobs, and our lives to promote security. Structure is necessary to function, but it cannot be the sole framework of our lives.

Deep chaos is at the other end of the continuum from structure. Just as we cannot maintain strict order at all times, people cannot function in constant deep chaos. It does serve a purpose. "Deep chaos is a natural, inescapable essential stage in the transformation of all life forms" (Merry, 1995, p. 13). Deep chaos results in either disintegration or a restructuring, or self organization, into a higher level of complexity (Merry, 1995). It can be a time of turmoil, uncertainty, and fear, but it is something all human beings experience at various points in their lives.

However, people can be continually self organizing without the extreme upheavals of deep chaos. The interaction between individuals and environments provides immediate change to restructure behaviors and interactions. We are constantly adjusting ourselves in relationship to society, environment, and relationship factors. Resilience (Merry, 1995) allows for systems to adapt and change without the major disruption of deep chaos. It is a characteristic every individual possesses and utilizes in varying degrees.

Variations in resilience can be noted in how people adapt to change in their daily lives. They may resist change by attempting to keep things the same, or maintaining equilibrium, which is contrary to the openness and interactions of daily life. Systems which avoid or delay changes may not be able to hold the equilibrium, and "the system reaches a state of instability where it can no longer continue" (Merry, 1995, p. 49). Then, it either decomposes or self organizes into a more complex order. Deep chaos can be a direct result of forced and maintained equilibrium.

Several levels of self organizing behavior can occur as a result of change. Merry (1995) describes these five levels as repetition, variation, adaptation, transition, and transformation. Often these levels of behavior occur in stages, one following the other when the prior one has not supported the self organization. Individuals try behaviors which are known, and therefore safe, first.

People will try the first levels of behavior before attempting the higher levels of behavior. "Most people will not make a deeper kind of change if they can get by with a lighter change" (Merry, 1995, p. 124). We try what has worked in the past and then proceed as indicated, modifying former behaviors, and finally trying completely new behaviors out of necessity. The new behaviors become part of the new emerging complexity of the individual.

Fear and uncertainty can interfere with transitions and transformations. These two new areas are full of unknown possibilities which can be paralyzing to an individual. "The far reaching consequences and the fear of the dangers of the unknown, and the chaotic transition period, tend to deter people...from making the quantum leap of

transformative change" (Merry, 1995, p. 125). Their refusal to make the move to a different level of behavior could lead to a complete breakdown.

Complex systems are related and interconnected. "Complex systems cannot exist in isolation. By their very nature they are tied to and connected to other systems, thus creating a dense web of connections...Affecting one system has repercussions in countless other systems" (Merry, 1995, p. 61). The openness and interaction among complex systems increases the complexity by the sharing and connectivity.

Martha Rogers presented the initial conceptual model of the Science of Unitary Human Beings in her 1970 book *An Introduction to the Theoretical Basis of Nursing* (Fawcett, 1995). Rogers' model was refined through several stages in later years which focused the language based on experience and actual application in practice.

Rogers identified ten assumptions which were the framework for her theory. (Fawcett, 1995).

1. Nursing is a learned profession.
2. The explication of an organized body of abstract knowledge specific to nursing is indispensable to nursing's transition from prescience to science.
3. Nursing is both an empirical science and an art.
4. Nursing science is an organized body of abstract knowledge arrived at by scientific research and logical analysis.
5. The art of nursing is the utilization of scientific nursing knowledge for the betterment of people.
6. People need knowledgeable nursing.
7. The practice of nursing is the use of nursing knowledge in human service.

8. The descriptive, explanatory, and predictive principles that direct nursing practice are derived from a conceptual system.
9. Nursings' long established concern is with people and their worlds.
10. People have the capacity to participate knowingly and probabilistically in the process of change. (p. 378)

The focus of Rogers' model is unitary, or irreducible, human beings and their environment. Human beings and the environment are unique and separate, and are not a reduction of parts of a higher model (Fawcett, 1995). The exchange between human beings and environment is open, constant, and ever changing. " The capacity of man and his surroundings to engage in a continuous interaction process rests on the fact that both are demonstrably open systems" (Rogers, 1970, p. 49). Therefore, individuals and their environment must be examined as context of one another.

The concept of energy fields has two distinct and contributory components: energy and field. Field implies the unity and irreducibility of human beings and environment. Energy describes the characteristics of the fields themselves (Fawcett, 1995). Fawcett (1995) quotes Rogers as stating "human beings and the environment are energy fields; they do not have energy fields" (p. 384). The words "energy" and "field" used together in this model are at the core of Rogers lifetime of work.

Energy fields are constantly open (Rogers, 1992). Openness is not a transitory or random phenomenon. It is a constant state of existence, interaction, and exchange between human beings and their environments. If human beings are energy fields, and environments are energy fields, an interface between them implies some transfer of

energy. As this is a continual state of existence, nothing remains constant and change simply happens at different levels for each human being.

As light has a wavelength, energy has a pattern. This pattern is a special and unique identifier of each human and environmental field (Fawcett, 1995). There is nothing static or linear within the concept of pattern. Rogers (1970) states life is unidirectional or one way; there is no regressing or repeating of life events. Patterns are constantly moving and changing, or becoming more complex and diverse.

Rogers originally developed four principles of homeodynamics to expand the understanding of the concept of pattern. The original principles were reciprocity, synchrony, helicy, and resonancy (Rogers, 1970). These principles evolved into three current principles, resonancy, helicy, and integrality (Rogers, 1992). Resonancy supports the level of change within human being and environmental patterns from lower to higher frequencies. Helicy is the essence of continual movement to more diverse patterns. Integrality is the connectedness and interaction of human beings and environment (Rogers, 1992). These three principles are used currently in the application of Rogers' theory.

Pandimensionality is a concept which frees the energy fields and patterns through the absence of borders and causative restrictions. Energy fields have infinite potential due to the absence of restrictions. The usual linear concepts of time, space, and being are seamless and connected at all levels. People are pandimensional; they do not become pandimensional (Rogers, 1992).

Nursing views a unified human being through synthesis and pattern seeing (Fawcett, 1995). Barrett (1998) takes Rogers' concepts one step further through the term

pattern manifestation appraisal. Pattern manifestation appraisal is "the continuous process of identifying manifestations of the human and environmental fields that relate to current health events" (Barrett, 1988, p. 50). It is the recognizing of patterns and variations and how they impact states of wellness.

Rogers steps away from societal definitions of health and illness in the Science of Unitary Human Beings. Health and illness are considered to be an expression of the life process (Rogers, 1970). She does not distinctly define these two terms within her model as they are linked to value structures of current society (Fawcett, 1995). However, individual patterns present upon some point of a continuum of potential and "vary in their expressions from greatest health to those conditions which are incompatible with maintaining life processes" (Rogers, 1970, p. 125). Wellness is the presentation of an individual's potential, whether that is physical, mental, or spiritual.

As health and illness are presentations of each energy field, nursing must expand its' view beyond strict parameters. There truly are no normal phenomena in the world, merely averages of the presentation of multiple patterns. Nursing must see the presentation of each individual just as it presents itself, without personal or societal restrictions. Only then can we assist in the movement to more complex and diverse patterns, or the unique possibilities that is within each and every one of us.

As each appraisal is unique to the energy field, so will the nursing interactions be unique to the discovered patterns and health potential. Each nursing interaction is not based on the provider or societal definition of health, wellness, or need, but solely on the presentation and potential of the existing self at that moment of openness, interaction, and

intervention (Fawcett, 1995). Nursing must complement the biomedical model with providing what a person needs.

Martha Rogers' Science of Unitary Human Beings expands nursing knowledge away from a reactionary and reductionary separatism of health, illness, and treatment to a unique, irreducible, and potential based model. Application of her theory would maximize the attainment of optimal pattern for every individual, no matter what his/her life circumstances may be. She has developed a paradigm specifically for nursing based on what merely is, not what it should be according to society or other disciplines.

This paradigm of what is reinforces the uniqueness of each experience. Two individuals can experience similar circumstances and perceive and interpret them in significantly different ways. Those unique perceptions exist for each one of us, and we derive significance and meaning from moments in our daily lives.

Human beings search for meaning, or "to act as a symbol of; signify or represent" (http://www.dictionary.com, 2004) in life changes, events, and challenges. People look to make sense of life and experiences through meaning (Coward, 1997). "In our struggle to make sense of ourselves and our world, we have often tried to explain or enact our feelings of isolation, separation, and longing" (Hope, 1997, p. 50). Meanings are as specific and unique as the people who create and apply them.

Dr. Victor Frankl has provided a school of thought in psychology dedicated to the search for meaning. Logotherapy comes from the Greek word *logos*, or meaning, and is a "meaning-centered psychotherapy" (Frankl, 1984, p. 104) which focuses on the future, instead of the past. Many other therapies are grounded in the concept of fixing something in the past, which reflects the person in the present.

Dr. Frankl states the search for meaning is a primary influence in the lives of human beings. It is not an overall search for the stereotypical meaning of life but a search for meanings of moments and experiences. "The meaning of life changes but never ceases to be" (Frankl, 1984, p. 115). The search, and ascribed meanings, is unique to each person. It cannot be dictated, given, or found for a person. He/she must define it for themselves (Frankl, 1984). "In effect, each person stands at the center of his or her own universe of meaning, transforming the flow of sensations into organized and intelligible events" (Barnlund, 1976, pp. 716-717). Everyone has a search for meaning, but he/she must discover it on his/her own.

If a person is having difficulty finding his/her definition and meaning, or a challenge of will to meaning (Frankl, 1984), they may experience existential frustration. People who are frustrated in the search for meanings of life experiences may choose other avenues in an attempt to find the meaning, such as various addictions. "Though people tolerate occasional doubts, few can accept continuing meaninglessness" (Barnlund, 1976, p. 716). The frustration cumulates in a phenomenon called the existential vacuum (Frankl, 1984, 1988).

The existential vacuum is "the feeling of the total and ultimate meaningless of their lives. They lack the awareness of a meaning worth living for...(and) are haunted by the experience of their inner emptiness, a void within themselves" (Frankl, 1984, pp. 110-111). This existential vacuum shows up in therapy as a listless boredom which a person has attempted to fill with money, power, or personal pleasures (Frankl, 1984). This behavior tries to fill a void in his/her life with intangible or material things.

Logotherapy turns away from the value judgements of the past of the typical psychiatric practitioner to the responsibility of the person for his/her future. "It must leave to him the option for what, to what, or to whom he understands himself to be responsible" (Frankl, 1984, p. 114). The person is responsible for finding the meaning in their life and proceeding on those meanings.

Human beings are searching for meaning in their lives at every single moment. "Being human always points, and is directed, to something, or someone, other than oneself-be it a meaning to fulfill or another human being to encounter" (Frankl, 1984, p. 115). There are three ways to discover the meanings contained within daily life: "by creating a work or doing a deed;...by experiencing something or encountering someone; and...the attitude we take toward unavoidable suffering" (Frankl, 1984, p. 115). These three actions are a core component of every single person's journey through life.

The search for meaning may also facilitate the attainment of health, or complex patterns, within illness, or degrading patterns. "Health is essential to the accomplishment of every purpose" (Pierce, 1895, p. ix). Lindsey (1996) states nursing needs to shift from an illness based paradigm to one that focuses on the person's capability and well being, based on their his/her own self. Health means wholeness (Hope, 1997), which is unique to each person. "And what nursing has to do in either case, is to put the patient in the best condition for nature to act upon him" (Nightingale, 1969, p. 133). What we are at each moment is continually changing, but what we are capable of is infinite.

As people search for meaning in their lives, they choose which construct applies to their experience, even if the experience is exceptionally challenging. "A human being, by the very attitudes he chooses, is capable of finding and fulfilling meaning in even a

hopeless situation" (Frankl, 1988, p. 75). Even as life gives people difficult situations, each has the capability of finding the meaning, or the proverbial silver lining, through choice.

As Martha Rogers has shown, people are irreducible energy fields. If we are truly unable to be reduced to isolated experiences and parts, every single thing which we encounter in our daily lives becomes the person, and impacts how people believe in and interact with his/her environment from that moment onward. "Any belief is based on something which he undergoes and experiences in his conscious awareness" (Bertocci, 1957, p. 12). We are different than we were five minutes ago, and will be different five minutes from now, simply due to the openness of the person/environmental energy fields.

People change through the vast experiences we gain in daily life. Our families, education, and culture provide us with a base of knowledge, or background meaning (Benner & Wrubel, 1989) to begin to find our way through life. "Our cultural history as it occurs in the present connects us to our past because it contains meanings that have been passed down" (Benner & Wrubel, 1989, p. 27). Information is taught and passed down from our families when we are young. Parents foster the growth and development of their children by sharing their own knowledge and experiences. This sharing of experiences provides a foundation for the child to live his/her life. As the world becomes more complex, so is the knowledge taught to each generation at younger and younger ages.

As people age, we gather meanings and experiences through our actions in our world. The results of those actions impact who an individual is, and gives him/her a basis to make future choices. We change as we age. Nothing is ever constant, but is

continually being refined though our experiences and our meanings and thoughts about those experiences. "Temporality means being anchored in a present made meaningful by past experience and one's anticipated future" (Benner & Wrubel, 1989, p. 112). Life is not conditioning, as it can be with other animals, but the process of applying current thought and past experiences to our future growth. It is a constant refinement of feelings, meaning, and perceptions through thought and experience.

People are conscious, thinking beings. The capacity of thought, reason, and choice is what defines a human being from other species. "Man...is a free, thinking being. He is not only a rational animal, but a free, rational animal" (Bertocci, 1957, pp. 27-28). Our experiences may influence our thoughts, but it does not predetermine our actions. "To say that a man is free to think, free to believe, then, is to say that whatever happens to him...what he believes about it depends not simply on what has happened, but on what he now chooses to believe..." (Bertocci, 1957, p. 23). We make decisions and choices because we have the free will to do so, or simply because we can.

Our choices are not without limitations. There is a result, or an outcome, of every single action we take. The outcomes and experiences will become the person. The outcomes will affect others, in varying degrees, as well, and those outcomes may be outwardly seen or may be invisible or unknown. "And a man is responsible for what he thinks and what he becomes because he is free" (Bertocci, 1957, p. 27). It is our responsibility as thinking, reasoning people to not make decisions and choices lightly.

A decision is made weighted on the experiences we have had and the thoughts about the outcomes, the choice is final cumulation of the decision process, and the will makes it happen. To will something requires conscious and focused effort, rather than

basic want or emotion (Bertocci, 1957). Will is the actions taken on our thoughts and experiences to actualize our choices.

People may realize the appropriate choice to make, but choose something different instead through their will. "Free will was defined as the power of persons to originate or being into existence the purposes or ends that guide their actions" (Kane, 1985, p. 22). Every person can make a choice, no matter what the circumstances or life experiences may be. People may not always be able to control what they think, but they can control what they think about something (Bertocci, 1957). The capacity to will is what makes each person unique. Each individual has it, but there are often variations in how it is utilized.

Willpower, or the "strength of the will" (http://www.dictionary.com, 2004), is the example of the presentation of the will. There are degrees of willpower in each person. For example, there is cheesecake being served for dessert. Based on our past experiences, we know the cheesecake is delicious. However, our clothes are fitting tighter than we would like. So, we choose not to have the dessert, based on that potential impact on our future. It is tempting, and other people are commenting on the cheesecake, but we choose not to eat it. The strength of the human will can overcome the simple temptation of a dessert, or carry us through some of the most trying times of our lives.

People have free will to seek out and choose the meanings contained within their lives. The meanings are about something, or about an object. Franz Brentano stated "what is characteristic of a thinking being is that it relates to something as an object" (Brentano, 1929, p.41). People relate to their life, relationships, and experiences through meaning. This relationship is called intentionality.

Franz Brentano (1838-1917) expanded on the concept of intentionality in modern philosophy. Intentionality is not an act which is completed on purpose, such as an intention to complete a task in the future; rather, it is a thought, or mental state that is about, related to, or directed towards an object (http://www.plato.stanford.edu/entries/brentano, 2004). "Intentionality means that consciousness is always consciousness of something" (Streubert & Carpenter, 1999, p. 45). Individuals have intentionality about every single facet of their daily lives, experiences, and outcomes.

Brentano (1929) stated there are three modes of relation towards an object. The three modes are presentation, judgement, and emotion. Presentation is merely how the object is perceived. Judgement entails a denial or a belief of the object, as emotion entails some form of love or hate of the object. The presentation, judgement, and emotion are so tightly interrelated in human beings that it is difficult to make a separation of the three modes. If we taste a food, there is an immediate judgement and related emotion about the food. Perhaps individuals who are able to carry out seemingly impossible feats, such as walking on fire and transcending torture, have learned to separate the presentation of the object from the judgement and emotion.

All of these theorists have reinforced the important concept of irreducibility. People are not a puzzle, made of many pieces, or a recipe, consisting of many ingredients, but are a constantly changing and complex energy field. This conceptual model attempts to capture the uniqueness of the human experience and presentation in daily life.

Assumptions and Components of the Conceptual Model

1. People are sentient and are capable of thought and reason.
2. People are capable of choice
3. People and their environments are irreducible energy fields.
4. People search for meaning in their lives and experiences.
5. The experiences and meanings of life become the person.
6. Change is constant and unavoidable.

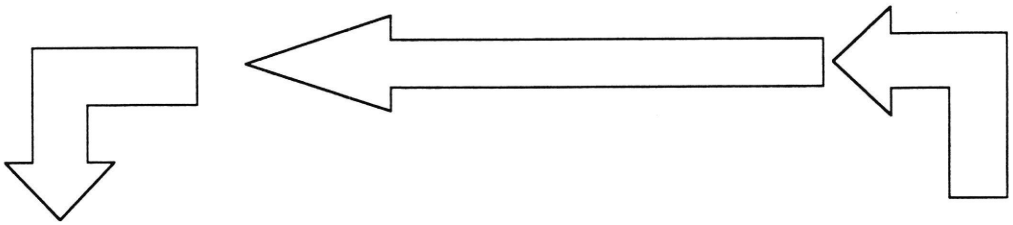
There are several components to the conceptual model which are presented in visual form.

1. Intentionality of Self
2. Impact of Intentionality of Self on Complexity Spiral
3. Impact of Catalyst Point on Complexity Spiral
4. Triad of Being

The visual form is limited by the restrictions of expression through the linear and single dimension of paper. However, the visualization of the model may assist in the understanding of the framework and application in any environment.

The first component of the model is *Intentionality of Self.* This component is a visual representation of several concepts which influence each unique being. The components outlined in this diagram are not linear and reactionary, but are continuous and instantaneous. The steps are broken out in order to support and illustrate the impact of meaning and choice upon being.

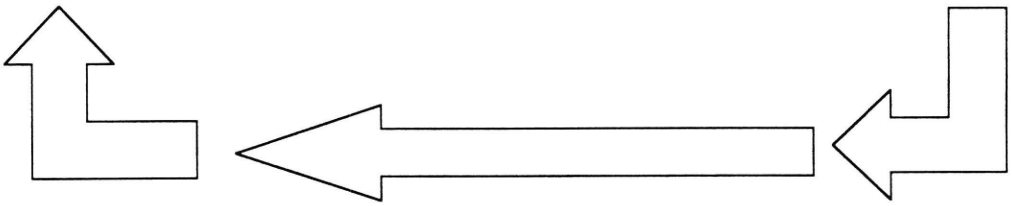
Intentionality of Self



Transcendence

Being **Experience** **Catalyst/event** **Meaning**

Stagnation

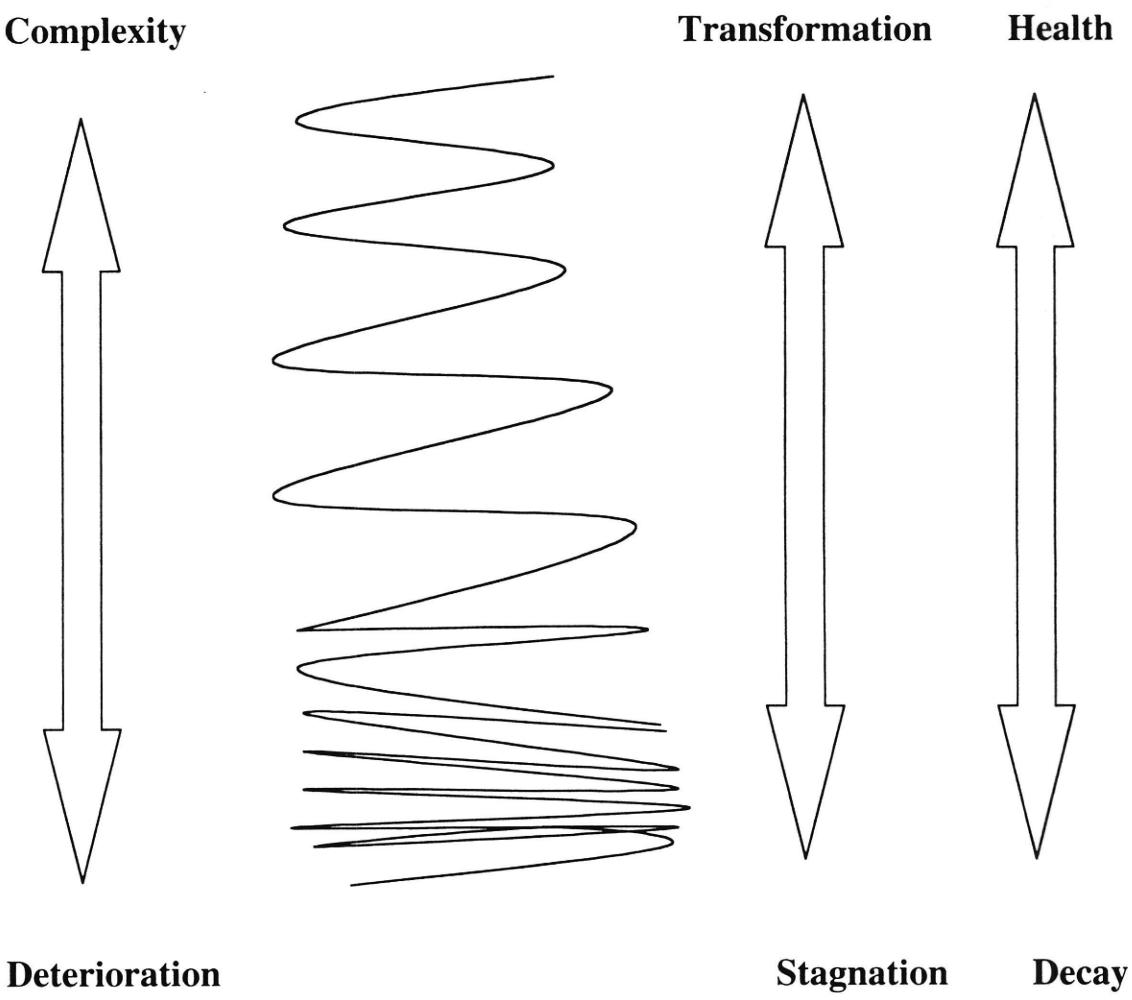


Intentionality is the bridge between consciousness and meaning. Human beings ascribe a meaning to the experience in order to find purpose in their lives. As human beings are capable of making choices, they choose stagnant or transcendent meanings of their experience. These meanings have a variety of foundational sources: society, culture, and self. However, no matter what framework these sources have provided a person, he/she is capable of a new and unique choice through free will. Information, experience, and other factors do not automatically predetermine meaning. People choose the meaning they ascribe to their experiences.

Since humans are irreducible, the choices each one makes becomes the individual, The chosen meaning becomes part of the being and consciousness, and impacts the self. Merry (1995) calls this iteration. "Iteration describes situations where something changes repetitively, in a way that each following change is effected by the change which preceded it. The results of one change are fed back to the system and serve as the basis for the next change" (p. 28). Iteration shows constant, ongoing change which becomes the person.

The presentation of the pattern can be visualized in the *Impact of Intentionality of Self on Complexity Spiral*. Merry (1995) calls the complexity spiral "the growth of complexity...in the human world" (p. 58). The complexity spiral is our life journey. It has periods of high complexity, states of degradation, and is the illustration of constant change. This illustration is not proportional to time; it can be a visualization of five seconds or five years.

Impact of Intentionality of Self on the Complexity Spiral



The inherent nature of patterns is to change, as illustrated in the upper levels of complexity and transformation. The openness of the complexity spiral illustrates the potential that exists at these levels. Human beings may choose either to transform or stagnate. Stagnant patterns oppose the nature of movement to more complex levels, and deterioration is a direct result. Patterns may become locked in this deterioration state and be manifested in episodes of decreased potential and functioning, as illustrated by the tighter areas of the complexity spiral.

Patterns may deteriorate to such extreme degrees they may degrade completely. It is hypothesized this is the cause of death when no biological factor can be found. Dr. Viktor Frankl describes this phenomenon as someone "who has lost faith in their future" (Frankl, 1984, p. 82). Loss of meaning and direction could potentially be as fatal as cancer.

Dr. Frankl saw many people lose their faith, belief, and spiritual hold in the concentration camps in World War II. He believed in the integrated relationship of the mind and the immune system. When the mind gave up hope and courage, the body was left susceptible to rampant disease and malnutrition (Frankl, 1984). The strength of the mind/body connection cannot be ignored.

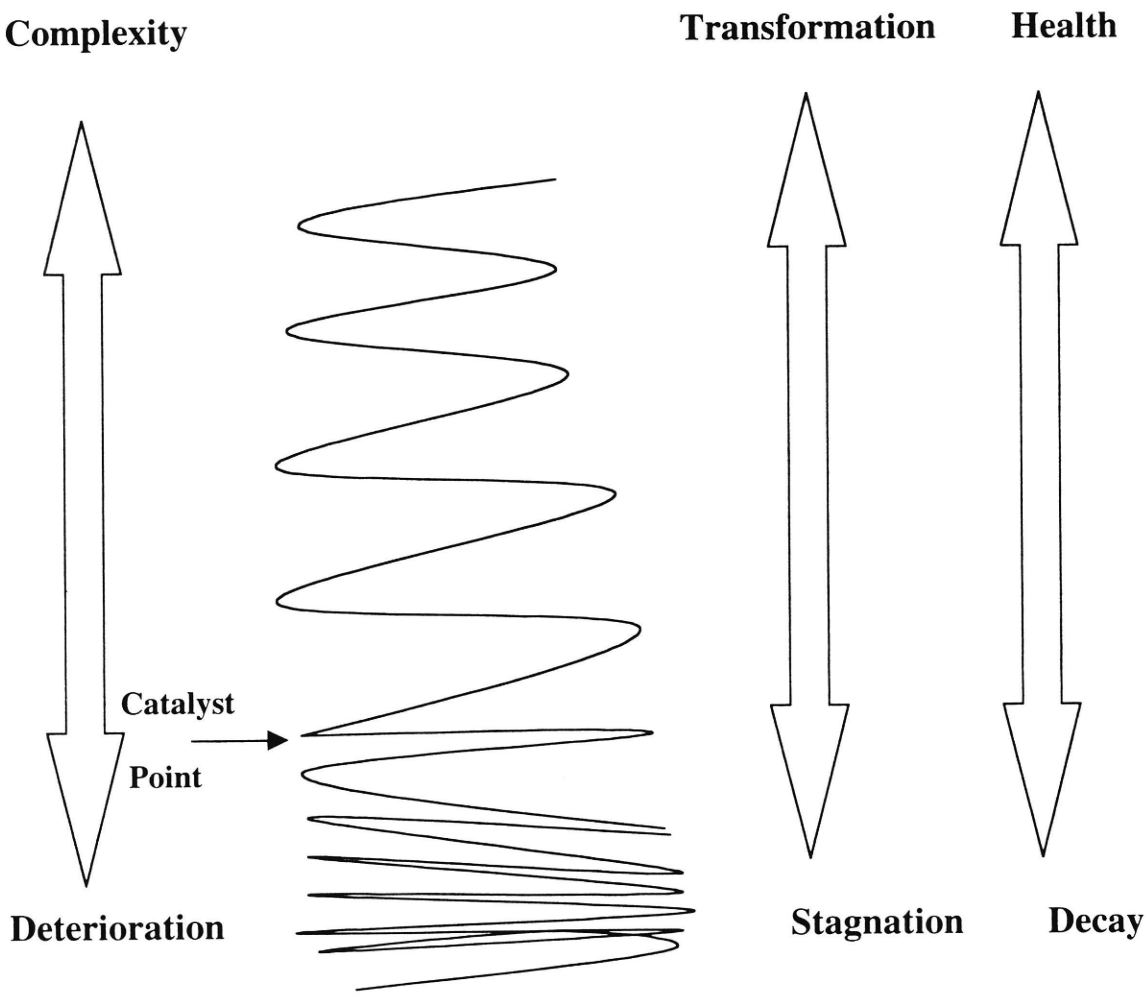
Human beings may also exist at complex levels of being under the most adverse of circumstances. A person may overcome their disease and show unexplained medical progress. Examples may include a recession of a fast spreading cancer, an increase of the immune system in a terminally ill HIV positive patient, or even the transcendence of the pain of a severe burn. Even Dr. Frankl was able to survive one of the most horrific times in modern history through his impact on other people.

Several scientifically unexplainable phenomena may exist at these complex levels of being. Extrasensory perception, déjà vu, and intuition may all be examples of manifestation and recognition of patterns at a more complex level. Physical manifestations of complex patterns interacting with environmental patterns may be found in the connectedness of twins and family, distance healing, telekinesis (moving objects with the power of the mind), telepathy (reading minds), and premonitions. As patterns become more complex, their presentations and capacities may become more complex as well.

If humans are moving to higher levels of complexity, it stands to reason environments are changing as well. Objects, places, or other manifestations of nature may also present with complex and diverse patterns. We may see presentations, or attributes, beyond what is usually expected or considered. Holy icons, haunted houses, or healing relics may be examples of complex patterns beyond the typical.

Events or interactions can impact patterns as illustrated in the *Impact of Catalyst Point on Complexity Spiral*. A catalyst is a "substance, usually used in small amounts relative to the reactants, that modifies and increases the rate of a reaction without being consumed in the process" (http://www.dictionary.com, 2004). The catalyst promotes patterns of self defined health and may assist in the movement of locked, decaying patterns to transformative, complex ones under any circumstances.

Impact of Catalyst Point on Complexity Spiral



This model proposes a compliment to the term "nursing intervention". Intervention, or to intervene, means "to come…between two things" (http://www.dictionary.com, 2004). As nursing is within the environmental energy field, there is no third party for nursing to intervene between. The action of the model occurs in the openness of the interactions between nursing and person.

When nursing performs an intervention, it is a linear, one way action. A pain medication is *administered*, an antibiotic *given*, or a treatment *performed*. All of these words show action upon something, from source to recipient. These types of interactions are performed using the current nursing process (Appendix C) (Iyer, Taptich, & Bernocchi-Losey, 1995). Certain tasks are action and outcome based, but are not characteristic of what is unique to nursing

There is one pair of entities medicine attempts to intervene between: person and disease. If a nurse performs an intervention between a disease process and an individual, it implies the disease is separate from the individual. Nursing interacts with people as a whole, not only as a disease process. This interventional approach is foundational in linear, biomedical treatment, but does not capture the complex essence of the nursing interaction.

Intervention also has a linear or power based connotation which implies the intervening party knows what is best for the recipient of the intervention. Nursing carries out many interventions as a bridge between other professions and patients. Nurses administer treatments, medications, and intravenous fluids to modify, alleviate, or correct a condition. Nursing does know what is best when these types of

interventions are completed. Skilled clinical assessment, and resulting appropriate interventions, are one, but not the only, critical skill set in nursing.

This is not an argument to delete the current nursing process completely. Nursing needs to be aware of the limitations, possibilities, and appropriate application of the nursing process. It is a linear, one sided, reductionistic approach to the person which potentially could be tainted by the nurse's world view and outlook. It is more of a closed system. "...mere technique and scientific knowledge is not enough" (Benner & Wrubel, 1989, p. 4). As the current nursing process is grounded in a biomedical approach and language, it has application in specific biomedical application.

Specific tasks, or the outcomes of the nursing process, are not the true essences of nursing. It is how the intervention is carried out which captures nursing interaction and contributions to individual health and potential above and beyond the physical plane. "Health is a basic resilience...based on the premise that all people, whatever their degree of health or illness and whatever their circumstances, have the potential for health. And health in this case is not simply a biological condition but also a mental and spiritual one" (Benner & Wrubel, 1989, p. 156). Nursing cares for the biological through interventions; it cares about the irreducible person through presence, participation, and polarization.

Intentionality of caring is an experience above and beyond physical assessment and interventions. As the energy fields of person and nurse are open and constantly interactive, the symbiotic relationship changes each field, ideally to more complex patterns, and leaves each one changed from the point of contact.

The intentionality of caring is illustrated by the *Triad of Being* (Figure 7). The Triad is illustrated as a defined model with distinct components for explanatory purposes

but exists as an integrated, interacting phenomenon which could act as a forum for a catalyst point. The Triad of Being includes: presence, participation, and polarization. The nursing process is how nursing carries out tasks, and the Triad is the context of the completion. This Triad of Being is unique to nursing and complements and supports the biomedical nursing process.

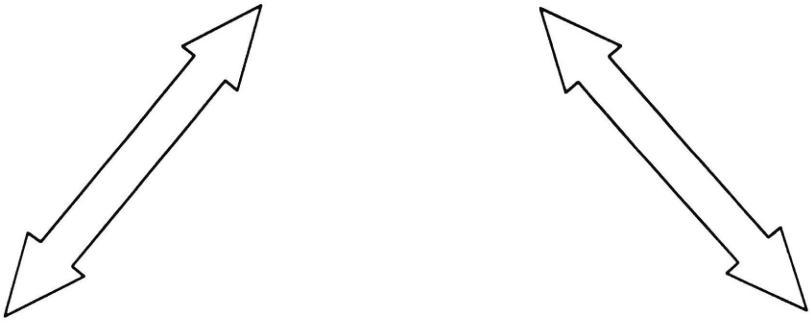
Triad of Being

Presence

Physical

Psychological

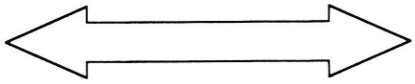
Therapeutic



Participation

(care about vs.

care for)



Polarization

(active,

collaborative,

and passive)

McKivergin and Daubenmire (1994) identified three levels of presence: physical, psychological, and therapeutic. Physical presence entails a "body to body" contact with sensory interaction. Psychological presence entails a "mind to mind" presence with a communicatory interaction. Therapeutic presence entails a "spirit to spirit, whole being to whole being, or centered self to centered self" (p. 70) with an interaction at a more complex level. This is the definition of presence used in the context of this model.

Participation is different from intervention. Participation entails "To partake of; to share in; to receive a part of" (http://www.dictionary.com, 2004). To participate in someone's life and experience is caring *about* them, not caring *for* them. *For* is "used to indicate the recipient or beneficiary of an action" (linear) while *about* entails "concerning; with regard to" (irreducible) (http://www.dictionary.com, 2004). Participation supports the openness and integrality of Rogers' energy fields. Participation also shows the nurse and the person are changed from the experience and interaction.

Polarization is a term usually used in the context of photography. A polarizing filter alters light waves entering the lens of a camera. The benefits of a polarizing filter include decreased glare and richer color. The filter does not change the color of the light, but the waves and reflections of the light (Grimm & Grimm, 1997). The appearance of the light, and resulting color, is then changed in the presentation of the printed image.

Nursing can polarize, or influence, the presentation of patterns in human beings due to constant change and interactions between energy fields. There are three levels of polarization: active, collaborative, and passive. Active polarization is a purposeful focusing or guidance of energy and pattern. This level of polarization is found in Reiki and therapeutic touch. Collaborative polarization occurs when nursing and the person are

involved in the change of pattern, such as within a teaching relationship. Passive polarization occurs by just being with an individual. The caring of the nurse impact the person through the openness and integrality of the energy fields. As human beings are irreducible, the impact of passive polarization changes the recipient's presentation.

Application of the conceptual model.

The model was applied with three women living with fibromyalgia who self report living with current or past life challenges or difficulties with health care professionals. The model was applied and evaluated through the activities of a structured health diary and interviews.

Peers of the interviewer were the contact and referral mechanism for potential participants. These people were asked if they would be willing to assist in networking for potential participants for the project. If they agreed to assist the interviewer, these peers were provided with a memo (Appendix D) providing the inclusion criteria for potential participants and other information. Peers were provided with preprinted contact cards (Appendix E) to give to potential participants with contact information for the interviewer. The potential participant had the option to contact the interviewer if she had additional questions or wanted to look further into participation in the project.

The potential participant contacted the interviewer via telephone or email. The interviewer provided them with additional information on time commitments and necessary activities. If the individual was willing to participate, formal written consent (Appendix F) was obtained prior to initiation of interviews. The participant was provided with a copy of the consent form for her records.

Once formal consent was obtained, the participant and the interviewer negotiated on a timeline for interviews and health diary exercises. The time and place for the interviews were mutually determined to provide for privacy and comfort. The participant was able to decline any questions or activities at any time. Contact phone numbers for supportive counseling were provided if discomfort or emotional distress occurred during any of the interviews.

The initial interviews had several functions. They provided an opportunity to share the participant's life experiences with fibromyalgia through historical recall and storytelling. The participant was asked to tell her story through a set of questions which addressed her life prior to and after diagnosis (Appendix G). The stories provided information on how the Intentionality of Self has impacted their current presentation. The interviews were also the space for the application of the Triad of Being.

Once the initial interviews were completed, the participant and the researcher made arrangements for the follow-up and closing interviews. The participant was provided with contact information for the interviewer if she had questions or concerns during the activity time. The interviewer also contacted the participant at the end of the first week to see if the participant had any questions.

The participants were provided with a preprinted fourteen day health diary which was completed on their own time (Appendix H). The first page contained instructions for completion of the health diary, such as defining the time parameters for each day and setting aside quiet time to complete the health diary. Concepts such as free thinking, quiet time, and privacy were all important elements (Starlanyl & Copeland, 2001). These

instructions were reviewed with the participant prior to the initiation of the health diary exercise. The personal and private nature of the health diaries was also discussed.

After the time for health diary completion had passed, the interviewer and participant met to reflect on the content. The participant was asked a series of questions specifically focused on the health diary activity (Appendix I). The participant was asked to discuss the actual health diary activity, the perceptions of the days the health diaries covered, and any challenges or surprises she encountered during the activity. They were also asked to choose the most and least successful days and were asked to talk about what defined those days.

The interviewer talked with the participant to independently identify trigger areas or potential areas for improvement in the future based on the content and insights of the health diary. Diary or journal keeping and reflection provided a record of activities that were helpful, as well as noting activities that may be triggers (Starlanyl & Copeland, 2001). It provided a tangible medium to examine and reflect upon in the future.

The closing interview included a set of questions discussing the overall experience of the interviews, health diaries, and closing interactions (Appendix J). The participants were asked about how it felt to tell their stories and complete the health diary exercise. They were also asked about how the overall project impacted their lives.

All interviews were audiotaped and identified by number only. These audiotapes were accessible only to the interviewer and transcriptionist and were erased after transcription. The audiotapes were delivered by hand in a sealed envelope to the transcriptionist for processing.

Each interview was transcribed into a two column table format. The blank column on the right hand side provided the interviewer with space to mark specific passages or to make notes on important concepts. All comments from the interviewer and participant were included for the final concept analysis.

The interview transcripts were initially read once for overall content. No notes were made at this time. Each transcript was then read multiple times to ensure familiarity. Colored highlighters were used to capture related concepts and longhand notes expressed the relationship between the data and the conceptual model. The noted passages from each interview transcript were then listed together and examined for related themes and quotes which would support or disprove the conceptual model.

The health diaries were read once by the interviewer for basic content. Each health diary was then independently evaluated for important concepts. The concepts from each health diary were then listed together and clustered into overall themes. The incidental data about sleep patterns, pain, and effectiveness of interventions were not evaluated.

Bracketing was utilized by the interviewer throughout the project "Bracketing is the cognitive process of putting aside one's own beliefs, not making judgements about what one has observed or heard, and remaining open to the data as they are revealed" (Streubert & Carpenter, 1999, p. 21). Bracketing assists the interviewer to remain more neutral during the project and to allow the project to unfold and present itself. The interviewer bracketed before and after each interview as "...bracketing must be constant and ongoing if descriptions are to achieve their purest form" (Streubert & Carpenter,

1999, p. 47). This exercise assisted in setting aside the interviewer's suppositions, past experiences, and hopes during the implementation of the project.

Chapter IV: Discussion and Evaluation of the Project

Evaluation of Activities

As the model was applied and evaluated through activities, the interviewer evaluated the impact of the health diary and interviews. Several commonalities were noted among the three participants. The overall benefits of participation were verification of fibromyalgia triggers and personal routines, and increased appreciation of good days, which was evidenced in comments like, "This is one of the worst days I've had in a long time. It makes me appreciate my good days", Increased support and awareness from social networks was also a benefit. One woman stated that this "...has made my husband more aware of what is going on...before we didn't discuss it much".

The health diary activity did not offer specific insights into fibromyalgia triggers, daily patterns, or management. It did serve as a verification of the participants' limitations and effectiveness of their treatment plan. "The sleep affects my fatigue level...I don't know if that was a big surprise, but it made me more conscious of it...It made me more aware of things" was an example of this insight. This reinforces Shaefer's (1997) findings that "knowing the self helps control the illness" (p. 568).

The health diaries and interviews provided concepts which defined successful or unsuccessful days while living with fibromyalgia. The primary characteristics of successful days were either physical in nature, such as adequate sleep, minimal levels of fatigue or pain, and a good attitude. "I woke up...not tired and my mood was great...I didn't have much stress in my day". Another indicator was achievement oriented, as participants were able to "do the stuff I need to do". Other achievements included completion of tasks and enjoyment of relaxation activities. "I enjoy it so I am going to

paint...garden. The pain is not going away if I sit here or if I garden". The quality time with their support network was also important. "I felt good about ...the quality time spent with my great niece". These statements support Shaefer's findings (1997) that "doing things that are pleasant and appealing helps to ease the discomfort" (p. 569).

The participants also stated it was beneficial to share their story, feelings and experiences with someone who was interested and understood what the experience of fibromyalgia was like for them. "I don't talk about my condition very often because people don't understand it and it is complex. This was good for me because you are interested and ...it is good to talk about it. Get out my feelings and stuff because I don't do that. People don't want to hear it." "We don't argue about it anyway...he (chiropractor) just shakes his head...we don't discuss it...". "I don't talk the them (husband's family) about my problems. I don't talk to anybody about it...except for people that have it".

Every participant stated she was reluctant to talk about their experiences to family and friends due to the invisibility and impact of fibromyalgia. "Nobody really truly cares how we feel. They have their own things going on and they don't want to hear about it". "My husband doesn't want to hear about it because he can't help me...it hurts him that I am hurting". These statements are examples of distancing from emotions (Benner & Wrubel, 1989) which can directly impact the effectiveness of coping.

One of the primary limitations of the evaluation of the health diary was that all of the participants had a formal diagnosis for five to ten years. Each participant had undergone formal treatment and had a primary treatment plan which worked for them. "I pretty much know myself. I pretty much know what is going to happen". The

participants also had a "plan B" for times when they knew their symptoms would be more challenging due to activities or environmental factors. "I just go easier. I guess that is plan B." "I try to do preventative stuff so I don't get into the problem and get run down." The life activities and management plans recorded in the health diaries were nothing new or different for these participants.

Initially, I had hypothesized the health diary exercise and interviews would provide the participants with a significant increase in the awareness of her triggers, current management plan, and other areas of improvement. The participants experienced benefits other than what was originally anticipated. This initial hypothesis specifically related to the health diaries could be evaluated with participants with new fibromyalgia diagnoses.

Other activities which allow them to share their insight with others may be beneficial to women with established fibromyalgia diagnoses. Potential activities could include peer or group support or mentoring of others with new diagnoses. Perhaps the sharing of knowledge with others with a new diagnosis would provide people with a sense of purpose and a positive benefit from their suffering.

Evaluation of the Conceptual Model

The model was evaluated through the life stories and experiences of the participants. The transcripts were examined for common trends and themes that would support or not support the proposed conceptual model. The interviewer found the experiences of these participants supported all components of the conceptual model and provided concepts and direction for further expansion.

The women shared stories which supported the Intentionality of Self. The participants shared several stories which illustrated how meanings, catalytic events, and experiences became part of their being. "I grew up with that (exaggeration of sick behaviors)...and I learned that is how you get out of doing things...I learned how. I was programmed." "I think I was one big ball of anger at that time." "You are walking around with this problem and there is nothing there...you really do think you are a nut case." "The life you knew has ended and you have a new life coming up and to look forward to it." These examples support the irreducibility of human life and intentionality.

The experience of living with fibromyalgia is a classic example of self organization. The participants stated they took one day at a time and adapted their activities and routines to how they felt that day. "It is a learn as you go process." As each participant has lived with fibromyalgia for several years, she was more attuned to what they were capable of completing based on how she felt. These experiences, through intentionality, became the participant, and influenced their future experiences.

The stories of the search for answers were also an example of self organization and pattern variation. Each participant discussed trying to live her life, doubting themselves and having a sense of relief once they had a tangible diagnosis. "Once I found out what was wrong with me the weight lifted." They felt they could move on with their lives once they had answers.

Shaefer (1997) found other women with fibromyalgia transition through stages when they receive a diagnosis. These stages are "recalling perceived normalcy, searching

for a diagnosis, finding out and moving on" (p. 566). Shaefer's stages reinforce the movement of pattern evident with the participants' experiences.

The participants showed evidence of many different types of catalysts, both biological and conscious, and how they affected her life. The catalysts were broken into three groups: transitory, mixed, and stationary. A transitory catalyst is something which moves a person through an experience or life event by encouraging self organization and increased levels of complexity. A stationary catalyst is something which hinders a person's movement and self organization. A mixed catalyst is something which could either move or hinder a person's movement and is dependent on context and how it is utilized. Appendix K and L demonstrates examples of internal and external catalysts and how they impacted the participants' lives.

Even though the participants had a formal treatment and management plan, they still had choice to live their lives and to do things outside of their normal routine. However, with these choices came outcomes, and the participants were aware of and accepting of these outcomes. One woman wrote she "did not eat well today...had a headache all night/evening." Another shared it is "like coloring your hair. You go backwards because it has salicylates in it...I won't go with gray hair...so you have to make choices". These statements reinforce the findings of Soderberg and Lundman (2001) which showed women with fibromyalgia attempt to move beyond the limitations of their disease to be viewed as normal. The participants knew there would be outcomes for not completing parts of their treatment plan or doing things that were not in their usual routines.

The consequences became evident when the participants pushed themselves past their personal limits to complete something important. Shaefer (1997) also found '"suffering results from doing things out of the ordinary routine" (p. 568). "My knee hurts a lot...due to moving all the furniture and standing so long at church." "I've been pushing myself too hard and it's starting to take its toll." They accepted how they would feel after completing their tasks, and adjusted their management plan accordingly.

The components of the Triad of Being were also supported within the relationship between interviewer and participant. The interviews attained the level of therapeutic presence, or "whole being to whole being" (McKivergin & Daubenmire, 1994, p. 70). This was evidenced by sharing of significant and private events by the participants. "I felt...more comfortable about it...I thought you wouldn't judge me. It is kind of personal." "I am going to tell you something that is really personal because it affected me a lot." The participants appeared to feel comfortable enough to share these events within the open relationship.

The open relationship was the participation noted in the Triad of Being. Even though I had a script of questions to ask each participant, each interview was distinctly different due to the variations of fibromyalgia, different life journeys, and priorities. The interviews were about the participants and what they had to share, not about me and what I needed to know. Participation can require some giving up of control, which can be exceptionally challenging in modern nursing.

The interviews also showed the level of collaborative polarization. Collaborative polarization was noted when changes occurred within the interviewer and participants through the interview activity. "It was really nice to meet you. That is something I am

glad about". "Your personality is great for something like this." "I am glad I was able to share this with you." I also noted changes in my own perceptions of life priorities and realization that we need make the most of each moment as your entire world can change in an instant.

Revisions to the conceptual model.

The interviewer became aware of several refinements to the model after the completion of the final interviews and reflection on the transcripts. The experiences of the participants reinforced the initial format of the model and provided insight into areas which had not been previously considered. These refinements provided more depth and detail about several components of the model.

The initial focus of a catalyst point was entirely external, such as between person and environment. An example would be a patient and health care provider. The interviews showed catalyst points can be external or internal in nature. Examples of internal catalysts include doubt, anger, and acceptance. Examples of external catalysts include support from others, sharing, and acceptance. As the environment can impact a person, so can the person impact himself/herself through internal strengths, characteristics, and conscious choices.

The initial definition of a catalyst point was the point of impact to move a pattern into more complex stages. The participants showed catalyst points can accelerate into more complex stages or hinder increasing complexity and cause episodes of stagnation. "I had surgery I didn't need which really sent me into a spin." Internal catalysts such as helplessness, sense of failure, and self pity caused stagnant, or challenging, points in their lives. External catalysts, such as minimizing of experience, disbelief, and judging by

others, also impacted their life journeys. The participants' experience showed catalysts can help or hinder them in any situation based on context and choices.

Catalyst points can compensate and counteract other opposing catalyst points. If an specific catalyst point causes an impact on pattern, another catalyst point can support it or oppose it, such as internal/internal or internal/external. For example, if a combination of external catalysts, such as weather, disbelief, and minimization from others could be counteracted with hope and positive attitude. As change is constant and the energy fields are continually open, two external catalyst points, such as support and weather, cannot counteract each other. There would be several internal/external points which would shape the end result.

The complete experience of the project showed the interviewer that catalyst points do not go only one direction but are multilateral. Multilateral catalyst points are evident through the open exchange of energy and continuing change. Both the participants and the interviewer came away from the project with changes and increased insight into their own perspectives on life.

IMPLICATIONS FOR ADVANCED PRACTICE

The health diary has shown to be an effective tool for capturing experiences, actions, and feelings. It is a medium which promotes accountability through recording, self awareness, and reflection. It also provides a sense of control over life and actions (Shaefer, 1997). The health diary could be an effective tool for people to capture the nuances of other diseases. Once something is captured on paper, it cannot be forgotten, discounted, or ignored. The information can be examined at our leisure and may either

serve as a way to obtain closure or to open doors. The structured health diary does have limitations as the format is biased by the viewpoint of the developer

Nursing could use formal or informal diaries to capture biological or reflective data. It could be used to gather information on activity levels, pain, fatigue, diet, and exercise or more personal things such as feelings, reflections on experiences, and the search for meaning. All of these things can provide nursing with insight into the various health disparities the person may be experiencing. Diaries can also give patients a safe place to express and organize their feelings and experiences to decide how to proceed in their lives..

What truly defines a health disparity? The obvious definitions include environment, access to health care, food, shelter, and resources. These components are the basic biological needs which we must all have to survive and to work towards the attainment of higher needs. These health disparities are visible and tangible, and therefore are easier to quantify and address.

But what about the health disparities at those higher levels? Do lack of personal and cultural respect, stereotyping, disbelief of personal experiences, and cookie cutter health care count as health disparities? I believe so. All of these things impact integrity, dignity, and personal value. Soderberg, et al., (1999) stated dignity was a unique personal characteristic. Once we have lost the importance of personal dignity and integrity, everything else is pointless.

People may not experience the standard forms of health disparities, but may experience barriers to finding their potential every day. Health care providers who interact with people based only on their own views have already set up barriers. Once we

have lost the individual and his/her unique needs in the maze of health care, we have lost the battle for the elimination of all forms of health disparities.

This conceptual model would be a valid tool for investigating the impact of populations experiencing any kind of health disparities at basic or higher levels. There are universal concepts which thread through every life, such as the uniqueness of personal perception and the search for meaning. Health care providers need to be aware there is more to each person than what the senses may perceive.

The conceptual model also gives advance practice nurses another perspective from which to view the life experiences of the people they interact with. This new viewpoint provides a perspective grounded in change, the search for meaning, and the potential which lies within each of us, no matter what our situation might be. The conceptual model takes the focus away from what society or individuals might define as illness and focuses on the uniqueness of each person, his/her lived experiences, and potential for the future.

Chapter V: Conclusions, Recommendations, and Reflections

Conclusions of the Project

I have concluded the original conceptual model is valid and applicable as a tool for nursing interactions and research. The interviews supported the concepts of self organization, continuous change, and catalyst points which all influence our transitions through our lives. The interviews with the participants validated the original format and gave me insight into expansion of the model.

The participants also provided deeper insight into the original conceptual model. The interviews provided more information on their experiences which were not originally considered. Components and definitions within the conceptual model were adapted and expanded to capture the processes.

Future Application of the Conceptual Model

Could the creation of rituals assist the catalyst process? "Ritual is an action that speaks to the mind and heart but doesn't necessarily make sense in a literal manner" (Moore, 1992, p. 225). Does ritual concretely bridge the gap between experience and meaning? "Knowing that everything we do, no matter how simple, has a halo of imagination around it and can serve the soul enriches life and makes the things around us more precious, more worthy of our protection and care" (Moore, 1992, p. 226). Or does ritual clarify the meaning?

The model could also be applied with people living their lives with a variety of manifestations. The risk of stagnancy and degradation apply to every individual everywhere, no matter where he/she is in their lives. Nursing can facilitate the expression

of complex patterns through the search for meaning and catalyst points with each person encountered

As the Triad of Being acts as a catalyst to assist people to achieve more complex states, any nurse under many different circumstances could utilize this model. The model is unique in that the application and outcome cannot be generalized to fit a practitioner, nor generalized to fit a clientele. It is the embodiment of the interaction of distinct, unique, and individual energy fields and therefore is specific in each and every application. Our humanity and irreducibility are our uniqueness and commonality for the application of this conceptual model in nursing.

Reflections on the project.

There is an immense difference between idealistically believing a theory is true and knowing it is true. I had practiced nursing for several years within a Rogerian paradigm without fully comprehending her concepts. This project has shown me that the openness of energy fields, continuous, unpredictable change, and the meanings of our experiences have a bigger impact than I had ever anticipated.

This project was a transformative experience for me through learning, self reflection, and my own self organization. It threaded through so many different parts of my life and was the highest of highs and the lowest of lows. It was more than just a paper to complete a degree; it was a definite chapter in my own personal and professional development. As Douglas Adams once said, "I may not have gone where I intended to go, but I think I have ended up where I intended to be" (http://www.quoteland.com, 2004). I have emerged with a whole new perspective on life, nursing, and where I want to go from here.

I have seen my life through the context of this model. There have been episodes of deep chaos, amazing catalysts, and constant self organization. This project has provided me with insight into my values, purpose, and contributions to society and the profession of nursing. I started out writing a paper; I ended up changing my life.

I learned the people we interact with impact us as well. I hope the three participants came away from the experience with something they can carry with them into the future. I know I certainly did. These three women shared some of the most challenging and terrifying times of their lives and how they changed and moved onward. Their dedication and determination inspired me to be more responsible and active in my own life while taking none of the daily pleasures for granted.

I learned the value of my own unique approach to nursing and the people I interact with every day. I touch patients, families, peers, and coworkers with my words and actions. This project helped me understand and value the impact even the smallest action or word has upon others. Even if my interaction with someone may appear to have no immediate, visible outcome, I still must choose my words and actions with care, as they may have a farther reaching influence than I realize. I must lead by example as my butterfly wings may cause that far off hurricane.

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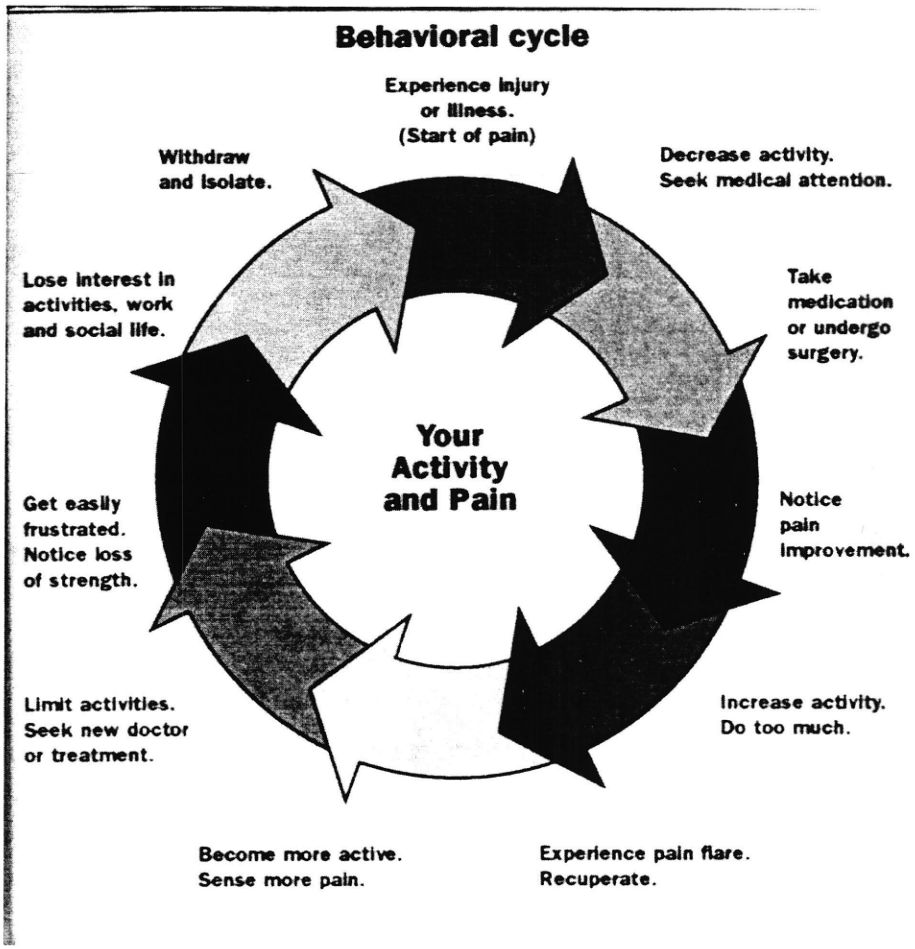
Appendix A

Behavioral Cycle of Chronic Pain



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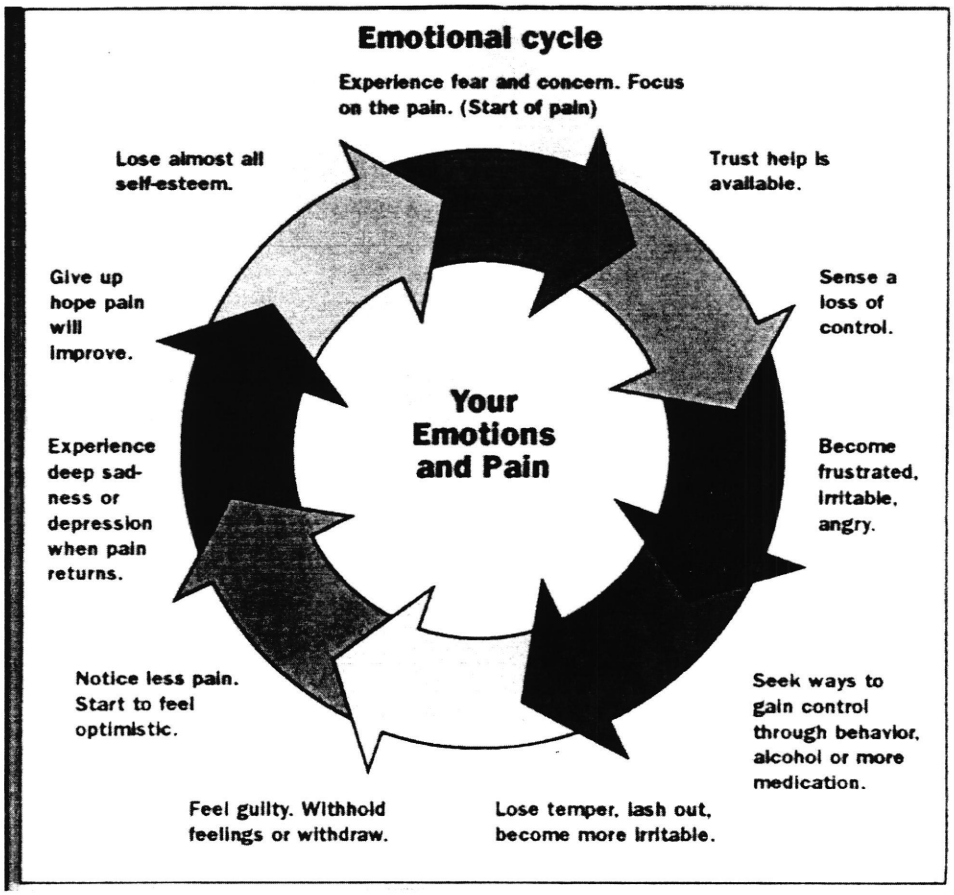
Appendix B

Emotional Cycle of Chronic Pain



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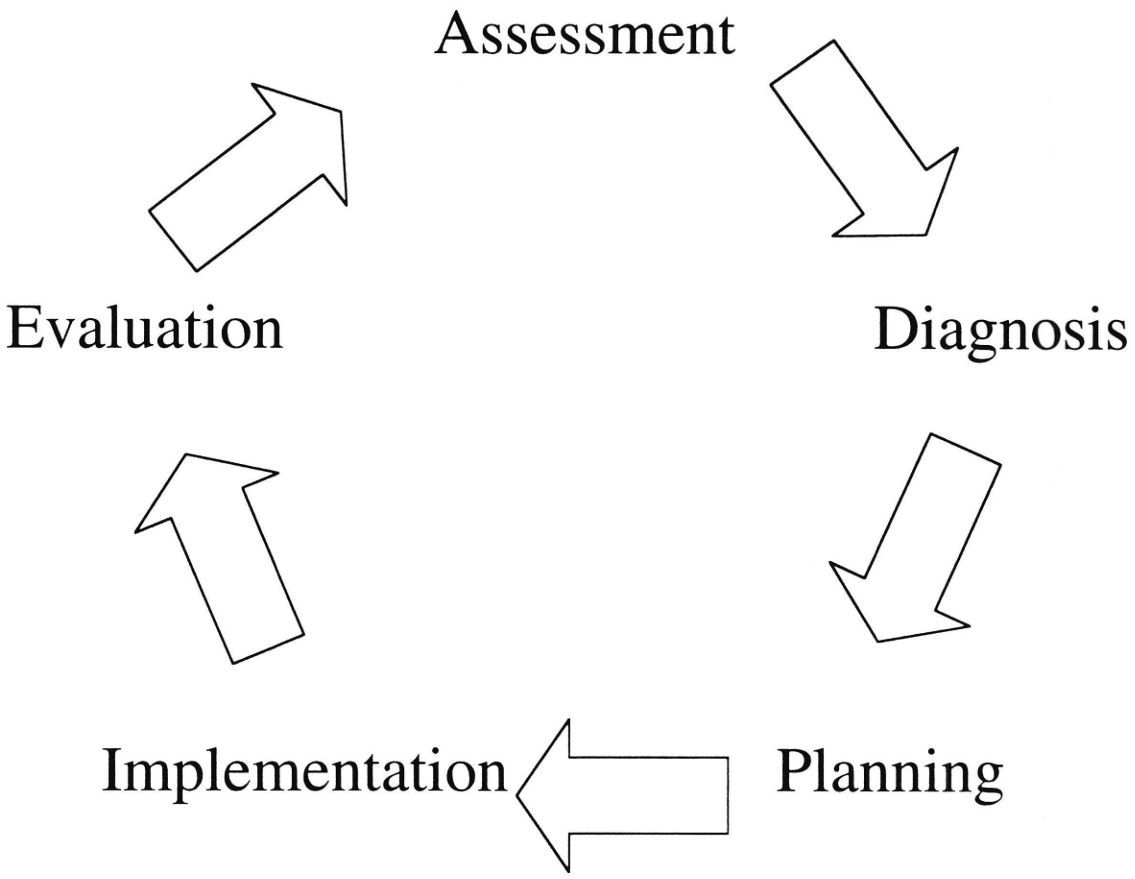
Appendix C

The Science of Nursing

Biomedical Nursing Process



Adapted from Iyer, Taptich, & Bernocchi-Losey, 1995.

Appendix D

Peer Recruitment Memo

To:

From: Brenda A. Becker, B.S., R.N.

CC: Sue Nash Ed.D., R.N.

Date:

Re: Masters project

I am looking for three volunteers for my masters project for my degree in nursing from Augsburg College. These three people need to fulfill the following characteristics to be able to participate.

- Female between the ages of 18 and 65
- Diagnosis of fibromyalgia
- s currently or has experienced challenges in their daily life living with fibromyalgia or interacting with health care professionals.

The object of the project is the application and evaluation of a new conceptual model through an activity. I will be interacting with these women through taped interviews and a health diary exercise. The health diary exercise would be a daily account of pain levels, activities, and pain management activities. The health diary will be recorded for fourteen days. The total interview time would be about four hours.

The resulting data will be evaluated by the participant and the interviewer for trends and triggers after the completion of the health diary exercise. The data from all the participants will also be evaluated by the interviewer for connecting trends and themes.

Please find attached a contact information card. If you know anyone who would qualify and may be interested in participating, please read the card to them and then give it to them. They can contact me if they would like to participate or for additional information.

Thank you!!

Appendix E

Peer Reference Card

A graduate student from Augsburg is interested in talking and interacting with women who have the diagnosis of fibromyalgia and are experiencing challenges with health care and living daily life for her masters project. There will be interviews and the completion of a health diary as part of the project. If you are interested in speaking with her and receiving more information, she can be reached at becker.brenda@mayo.edu **or at 507-358-9696.**
A graduate student from Augsburg is interested in talking and interacting with women who have the diagnosis of fibromyalgia and are experiencing challenges with health care and living daily life for her masters project. There will be interviews and the completion of a health diary as part of the project. If you are interested in speaking with her and receiving more information, she can be reached at becker.brenda@mayo.edu **or at 507-358-9696.**
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Appendix F

Consent Form

You are invited to be in a project examining the impact of nursing interactions within an interviewer/participant relationship. You were selected as a possible participant because you are a woman with the medical diagnosis of fibromyalgia who has experienced or is experiencing challenges with health care and/or living your daily life. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

I am conducting this project as part of my master's project in nursing at Augsburg College. My advisor is Sue Nash, Ed. D., RN, and you can contact her at any time during this project.

Background Information:

The purpose of this project is to examine how the interactions affect you through interviews and other activities, such as storytelling and the completion of a health diary. The information you provide through interviews and the diary will also be examined for important themes.

Procedures:

If you agree to participate in this project, we would ask you to do the following things:

1. Participate in two to three one hour initial interviews with the interviewer talking about your experiences with fibromyalgia and the health care system.

2. Complete fourteen days of a preprinted daily health diary, which would include information on activity, pain, sleep patterns, and what you did to manage your fibromyalgia.

3. Participate in one 1 hour reflection interview to reflect on the health diary to look for areas of success or improvement in your management of fibromyalgia. The time for keeping the health diary will be fifteen minutes per day or more, at your discretion.

4. Participate in one 1 hour exit interview to talk about the interactions and your experiences during the project.

Risks and Benefits of Being in the Project:

The project has risks: First, you may experience emotional or physical discomfort related to the discussion of your health history. You may experience various emotions and memories during the interviews or diary activity.

The direct benefits to participating in this project include a potential increase in your knowledge of your management of fibromyalgia through interviews and the health diary. The interviewer will also learn about your experiences of living with fibromyalgia. Any changes in your behaviors as a result of your interactions with the interviewer should be discussed with your physician.

Indirect benefits to participation are the contribution to the understanding of the experience of living with fibromyalgia.

In the event that this project results in an injury, treatment will be available, including counseling and follow-up care as needed. However, payment for any such treatment must be provided by you or your third party payer, if any (such as health insurance, Medicare, etc.).

Resources, which are available, include your primary physician, local hospitals and urgent care. In addition, the following resources exist for appointments.

Mayo Clinic Pain and Fibromyalgia Clinic	1216 2nd Street SW	507-255-8161
Olmsted Medical Center Clinic (Dr. Ammar)	210 9th Street SE	507-288-3443

Confidentiality:

The records of this project will be kept private. In any sort of report published, information will not be included that will make it possible to identify you. Every attempt will be made to keep the findings confidential but due to the small number of participants, anonymity cannot be guaranteed. Records will be kept in a locked file; only the interviewer will have access to the records.

The audiotapes will also be kept in a locked file. They will only be accessible by the interviewer and the transcriptionist. The audiotapes will be erased after transcription.

Raw data will be retained but all identifying information removed at the completion of the project. Only the interviewer, project advisor, and transcriptionist will view the raw data.

Voluntary Nature of the Project:

Your decision whether or not to participate will not affect your current or future relations with the interviewer. If you decide to participate, you are free to withdraw at any time.

If you desire to stop your participation in the project, inform the interviewer via telephone, email, or face to face contact. The interviewer will provide contact numbers for support resources, if so desired, at that notification. The interviewer will also have the option to ask you if you would like terminate your participation in the project if it is evident you are experiencing undue discomfort or stress, which could be detrimental to you or the project.

Contacts and Questions:

The interviewer conducting this project is Brenda Becker, B.S., R.N. You may ask any questions you have now. If you have questions later, you may contact them at becker.brenda@mayo.edu or at (507) 358-9696. The project advisor is Sue Nash, Ed. D., R.N., and can be reached at nash@augsburg.edu or (507) 281-6379 You will be given a copy of the completed form to keep for your records.

Statement of Consent:

I have read the above information. I have asked questions and have received answers. I consent to participate in the project.

Signature _____ Date_____

Signature of investigator _____ Date_____

I consent to allow use of my direct quotations in the report or resulting published project paper.

Signature _____ Date _____

I consent to be audiotaped.

Signature _____ Date _____

I consent to have a third party transcribe the audiotape

Signature _____ Date _____

Appendix G

Initial Interview Script

How long ago did you first notice something was changing with your health?

What did you notice?

How did those changes impact your daily life?

What did these initial experiences mean to you?

Did you make any changes to your daily life because of what you were experiencing?

How long of a time period passed between your noticing a change and seeking health care?

What were those experiences within the health care system like for you?

Does any one instance stand out for you?

How much time passed between your initially accessing health care and being diagnosed?

How did that make you feel?

What did your health care team recommend for a treatment program?

Are you doing anything else in your daily life to compliment that treatment program?

How is your life today?

Appendix H

Health Diary

Page 1 of the daily journal

Circle day: Su M T W Th F S

Please list the symptoms you experienced today, what you did for them and circle the number (1 = not effective; 7 = very effective) that represents how effective your self care was.

Symptom	Intervention	Effectiveness (Not 1 2 3 4 5 6 7 Very)
_____	_____	1 2 3 4 5 6 7
_____	_____	1 2 3 4 5 6 7
_____	_____	1 2 3 4 5 6 7
_____	_____	1 2 3 4 5 6 7

Please draw a slash through the line below that represents the pain you had today.

no pain _____ excruciating pain

What one word would you use to describe your pain today? _____

Please draw a slash through the line below that represents how

a. well you slept last night,

not well at all _____ very well

b. and how tired you were this morning,

extremely tired _____ not tired at all

Please identify one word which describes your mood today. _____

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Appendix H

Health Diary

Page 2 of the daily journal

Please circle the number that represents your level of stress today with 1 = no stress and 7 = a lot of stress.

1 2 3 4 5 6 7

Menstrual cycle: On hormone replacement

Progesterone Estrogen

Continuous

Cyclical

Menstruating

____ day of my menstrual cycle

The weather is (Circle all that apply): cold hot

warm

damp dry

rain snow

sunny cloudy

other: _____

Please briefly describe what you did today.

ADDITIONAL NOTES (Tell me anything else you think is important for me to know about your day.)

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Appendix H

Health Diary

SUMMARY PAGE

Please circle the number that represents your general quality of life for the last month.

worst possible 1 2 3 4 5 6 7 8 9 10 best possible

Please list the drugs you take routinely.

1.

2.

3.

4.

5.

6.

7.

8.

9.

10.

List any foods that bother you or foods that you avoid because they have bothered you in the past.

1.

2.

3.

4.

5.

How old are you? _____ years

When were you diagnosed with FM? _____ (year)

Do you attend a support group for FM? A Lot Sometimes Never

If you attend a support group, how does it or doesn't it help you?

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Appendix I

Health Diary Evaluation Script

Describe how the diary process went for you.

How did it make you feel?

Which day was your best day and why?

Which day was your worst day and why?

What were the challenges to the diary?

Were there any benefits to the diary?

Did you discover any surprises during your diary experience?

Were there areas you noted went very well or areas you would like to improve on?

Where there any triggers or areas you noted you could keep in your mind for the future?

Appendix J

Project Evaluation Script

What was this overall experience like for you?

What did you experience during the interviews?

What did you experience during the completion of the health diary?

Did you gain any insights during this process?

What was it like to share your experiences with me?

Did you discover any benefit during your participation?

Was there anything difficult for you during your participation?

How do you feel at the completion of the project?

Is there anything you would like to share?

Appendix K

Internal Catalyst Points

Name	Type	Example
Self organization	Transitory	"I adjusted to the pain." "It helped me a lot to get moving and focusing on other things." "...it was a big change...today I am going to have to learn to sit around part of the day." "It is a learn as you go process...it is an evolving thing."
Hoping/Wishing	Transitory	"I hope I get more done on Friday morning." "I hope I feel better tomorrow." "Wish I could sleep like that more frequently."
Determination	Transitory	"That is how I got through it. I kept pushing." "I am determined that way.": (sticking to diet). "It just made me more determined to find out what was up." "This is the way I have to do things, like it or not." "I just quit smoking. I am lucky that way. I am determined."
Acceptance	Transitory	"...most days I can accept my situation allowing that number (quality of life) to be higher." "When you can accept that it is there and move on...it doesn't bother you as much." "I think I would be satisfied with this." "That helped me assert myself...stand up for myself and be accepting of myself."

Self care	Transitory	"But taking care of yourself so something you aren't used to doing." "It still comes down to taking care of yourself and realizing your limitations." "I just try…to have a little control and…try not to overextend myself and take it easy when I need to take it easy."
Involvement	Transitory	"It gave me a lot of power by taking care of myself." "I follow instructions really well and if it is to my benefit, I am going to do it." "I am not giving up my health because somebody can't handle it." (limitations) "Once I figured out…I feel better when I do what I should do…then it is easier."
Perseverence	Transitory	"I made it through." "I got through it." "I just knew there was something wrong. I will just keep trying." "I said the heck with all these people and went on my own." "You just find ways to make it work." "It's kind of a mind game that I can do this, you can get through this, and I do." "I asked some questions too about what is going on here, how come I don't ever get better?"

Exploration	Transitory	"I realized that there was something wrong…that is when I started with the food and exercise…I read all kinds of books." "I figured it out on my own. (find a plan that worked). It wasn't them." "I did everything I thought would help."
Attitude	Mixed	"I work really hard on attitude. That gets me a lot farther than pain medication." "To make it a good day, my attitude needs to be in check." "Just be upbeat." "You don't want to give into it. It makes you crabby…I celebrate every day that is a good day or even half a good day."
Anger	Mixed	"Anger had taken over …because I was going through so much and I couldn't find any help." "Anger is a good thing sometimes. It gets you moving and gets you out of your pity pot." "It was easier to be angry and it gave me more power…before I was a wimp." "I certainly would have been mad enough not to get better."

Frustration	Stationary	"I looked fine and that was very frustrating." "That (tasks) frustrates me because I can see it but can't do anything about it." "When I am limited, that is frustrating." "Like the upstairs...it is so frustrating...because my knees are in too much pain." "It's hard to see everything not done. Then you get frustrated." "It was frustrating at times...it was hard for me to learn to make those changes in my personal life I had to make."
Pain	Stationary	"I am tired of it. I was in so much pain." "The pain bothers me a lot so it makes me agitated."
Fatigue	Stationary	"I'm too tired after work to cook supper."
Doubt	Stationary	"I'm beginning to wonder if I'll ever get relief from the...pain." "You really do think you are a nut case." "When you are always feeling bad and there is never any reason for it, it begins to affect your mind."
Self pity	Stationary	"(anger) gets you moving and gets you out of your pity pot...I didn't sit and worry about this pain all the time." "When my attitude is done then it is poor me and then I really struggle."

Sense of failure	Stationary	"I used to do our taxes…I started slipping and I thought what is going on here." "I should get up and do this or that."
Helplessness	Stationary	"I am beaten here, I can't do anything.". 'It went on and on for such a long time."
Minimizing of experience	Stationary	"It didn't matter how sick I was, I wasn't sick and I would get up and get things done." "I always figured it was injuries or working like a dog when I was a kid and I was always paying for it."

Appendix L

External Catalyst Points

Name	Type	Example
Concrete diagnosis	Transitory	"Once I found out what was wrong with me, the weight lifted. It wasn't all in my head and it was a tremendous relief to know there was a reason for all these things." "After I found out what was wrong with me...my life has totally changed." "The relief of knowing." "I don't know where I would be if I hadn't found that (diagnosis) out."
Involvement of others	Transitory	"So I have to have help to get things up there (upstairs). Then I can do things." "I know it was a terrible time for me and they (physical therapists) got me through it in a very positive way."
Support from others	Transitory	"My friends are such great support...It helps to keep my spirits up for we have become a tight knit group." "When I went to (supervisor), she is real supportive." "We (the water class) are in a really good therapy group because we understand the other person...and we don't take it personal as truly complaining...the emotional support...that I get from that group...is very very good."

Acceptance	Transitory	"Accept it and I will be there." (a family function). "Accept I have limitations and that I can't do everything I used to do and accept me as I am." "I was really lucky having...doctors that said 'I don't know what it is, but let's try to figure it out'. That admission gives you a sense of relief that someone believes you." "You need some sympathy when you first find out what it is and someone who is understanding."
Sharing with others	Mixed	"Like my husband doesn't want to hear about it because he can't help me...and it hurts him that I am hurting." "I don't want to burden them with something that can't be changed...If I really need to talk to somebody, I can find somebody." "My mother has stuff to read about it and she understood, but my dad doesn't at all."
Treatments	Mixed	"Being in the pool helped so much." "Some days nothing works, but water classes still help". "I had knee surgery that I didn't need, which really sent me into a spin."

Weather/Climate	Mixed	"Weather can make a difference." "I know different climates make a big difference too." (pain). "I feel better in the summer…I don't feel good when it is cold." "The weather had great influence on me."
Responsibilities	Mixed	"It takes awhile for me to recuperate after the weekend." (work)
Learned behaviors	Mixed	"Everything was exaggerated…because they were so sick and couldn't carry on…I learned that is how you get out of doing things…I was programmed."
Minimizing of experience	Stationary	"Then you need to go to the doctor and if he doesn't listen to you, find another." "…it irritated me because I needed to know and somebody wouldn't listen to me."
Judging by others	Stationary	"I thought about all the personal things I had told Brenda and felt rather embarrassed and guilty, thinking she would judge me." "The other thing…that took me down a lot was people not understanding and judging." "People judege you and don't allow you to be yourself."

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Disbelief	Stationary	"It was so devistating to me because I thought there was something wrong with me and nobody believed me." "They can't figure out what is wrong with you, they push it aside." "You had been hiding this for quite a while because everybody thinks you are crazy anyway."
Uncertainty of diagnosis	Stationary	"I well didn't know what was wrong with me or what was going on here." "No one finds out what is wrong with them...it is such a struggle...people thought I was nuts...myself included." "Every year I would go in...and my doctor would draw my blood levels. Nope." (menopause causing symptoms).